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The impact of Motor Neurone Disease on oral health: a scoping review

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Abstract

Objective: To identify current evidence on oral health-related quality of life in people with Motor Neurone Disease (MND), as well as identify barriers to oral health and care, and establish priorities for future research.

Methods: A scoping review was conducted. Electronic databases and grey literature sources were searched from 2000 to 2024. Articles discussing oral health in adults with MND were included. Findings were supplemented by stakeholder consultation with people with MND, caregivers, clinicians, and researchers.

Results: Fourteen articles met inclusion criteria, comprising eight cross-sectional studies, one prospective quality improvement project, one single centre observational and four review articles. Five key themes emerged: dental status and oral hygiene activities, orofacial function, secretion management, service delivery and Oral health-related quality of life (OHRQoL). Studies indicated that MND negatively impacts oral health through impaired ability to perform oral hygiene and altered orofacial functioning. Only one study examined oral health-related quality of life. Stakeholder consultation highlighted additional concerns including challenges with service access, the impact of MND on oral health, and difficulties maintaining oral hygiene due to physical limitations.

Conclusions: Oral health remains an under-researched area in MND care despite its potential impact on quality of life and overall wellbeing. Future research priorities should include investigating relationships between oral health and MND outcomes, improving service delivery models, and increasing dental professional awareness. Active involvement of people with MND in research design and implementation is essential for developing effective interventions.

Keywords

Oral health, Motor Neurone Disease, Dental, Oral hygiene, Secretions

Introduction

Motor Neurone Disease (MND) is a rare, neurodegenerative condition, characterised by progressive degeneration of upper and lower motor neurons, the underlying pathological mechanisms of which are still not well understood. This leads to muscle weakness and eventual paralysis, with associated respiratory compromise and death.¹ Presentation of MND can vary between its subtypes, with some individuals presenting with spinal-onset symptoms resulting in limb weakness, whilst bulbar-onset symptoms include difficulties with speech and swallowing.^{2,3} No cure exists for MND, and key aims of care include the management of symptoms, provision of support for the individual and their families, and maintaining quality of life. This care is delivered by a specialist multidisciplinary team (MDT), who support the various physical, emotional, and social needs of this group.⁴

The Fédération dentaire internationale (FDI) World Dental Federation definition of oral health is broad, defined as “the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort, and disease of the head, face, and oral cavity”.⁵ OHRQoL is a complex multidimensional construct reflecting factors such as comfort while eating, sleeping, during social interactions, self-esteem, and satisfaction with respect to oral health.⁶ It may impact an individual's overall perception of their general quality of life and is an integral part of general health and wellbeing.⁷ Whilst oral health is acknowledged as being linked to aspects of care such as cough and secretion management, it is often neglected in MND MDT management.⁸ Little is known about the oral health experiences and preferences of people with Motor Neurone Disease (pwMND) and how this impacts their quality of life.⁹

Muscle weakness, reduced mouth opening due to jaw spasticity, and dysphagia are likely to impair an individual's ability to perform daily mouth care activities resulting in reliance on third party support, and reduce their ability to attend dental appointments and receive dental care. As well as this, key areas of MND care include pharmacological management of excess secretions and use of non-invasive ventilation (NIV) to sustain life which may result in xerostomia.⁴ PwMND may also be placed on nutritional supplements, such as high calorie food and drinks,⁴ which are likely to increase an individual's risk of developing dental caries.

The oral cavity is linked to the gut both physically and chemically, and directly connects to the lungs. While innate physiological mechanism of airway protection prevent overt transfer of saliva and bacteria between the two, in conditions such as MND these safeguards may fail due to swallowing difficulties, resulting in increasing risks of

aspiration pneumonia and associated morbidity and death.¹⁰ Multiple studies, not specific to MND, have suggested the role of poor oral health as a risk factor in the development of aspiration pneumonia, due to build up of bacteria in the oropharynx.^{11,12,13} When oral intake of nutritional and medication is no longer considered safe, enteral feeding such as percutaneous endoscopically placed gastrostomy (PEG) and gastronomy tubes may be placed to aid feeding. PwMND may have reduced oral clearance leading to the development of calculus, further impacting on oral health status.¹⁴

The aim of this study is to identify what is currently known about the OHRQoL of people with MND and gaps in oral care delivery. Through stakeholder involvement, it also aimed to identify barriers to oral health for pwMND. It also aimed to identify gaps in research about the impact on MND on oral health and make recommendations for future oral health research priorities to improve access to oral care.

Method

A scoping review was conducted based on the stages described by Arksey and O'Malley,¹⁵ and allowing a broad exploration of the literature.¹⁶

Inclusion criteria were:

- English language articles
- Articles discussing adults (18 years+) living with MND
- A focus on oral health in relation to general dentistry (including caries, periodontitis, dental status, xerostomia, orofacial pain, Temporomandibular Disorder (TMD), bruxism, burning mouth syndrome, jaw movement, chewing difficulties, swallowing difficulties, sensory disturbances, self-reported oral health, oral health-related quality of life)

Exclusion criteria were:

- *in vitro* or animal-based studies

- Experimental, diagnostic or treatment methods outside the routine scope of general dental practice e.g., delivery of Botox to salivary glands
- Case reports, book chapters, short communications, conference proceedings, letters, and comments
- Articles not published in English

Search terms:

(“motor neurone disease” OR MND OR “amyotrophic lateral sclerosis” OR ALS OR “Lou Gehrig’s Disease” OR “Bulbar onset MND” OR “bulbar onset motor neurone disease” OR “Progressive bulbar palsy” OR PBP OR “Progressive muscular atrophy” OR PMA OR “Primary lateral sclerosis” OR PLS) AND (“oral health” OR “oral hygiene” OR “oral care” OR dental OR dentist*)

Electronic databases searched included Web of Science including Medline, Scopus, grey literature databases Overton and Ethos. National Institute for Health and Care Excellence (NICE) guidelines and the charity website of the UK Motor Neurone Disease Association (MMDA) were also reviewed to assess current published guidance on oral health management of pwMND, although these were not included in the inclusion criteria or final review. A librarian was consulted to support the initial search, completed in September 2023 and repeated in October 2024 which included papers published from 2000 onwards. Hand searching of dental journals including Dental Update and the Journal of Disability and Oral Health were completed, as well as hand searching of article reference lists.

The results were exported to reference management software Zotero and duplicates were removed (JT). Titles and abstracts were screened for inclusion into the study (JHD), and identified articles underwent full text review (JHD). Where there was uncertainty about a study meeting the inclusion criteria, this was discussed with a second reviewer (JT). Where there was still uncertainty, a third reviewer (EH) was consulted.

A data extraction template was used (Supplementary File 1), and initially piloted on 6 articles to aid consistency of information extracted (JHD, JT) before all 14 final articles were reviewed. Data extracted included article title, authors, date and country of publication, journal, sample size, oral health outcome measures and an outline of

pertinent findings and notable limitations. A formal quality assessment was not completed as this is not typically required in a scoping review.¹⁶

Results

An electronic literature search of the databases identified 1862 articles, of which 1834 were excluded after reviewing the title and abstract. A further 19 were excluded after full text review. An additional five papers were identified through a repeated electronic search in 2024 and hand searching reference lists. After full text review, 14 articles were included in the final review. Figure 1 (Supplementary File 2) shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses: Scoping Review (PRISMA-ScR) flowchart of study selection.

Study characteristics

Articles included eight cross-sectional studies, one prospective quality improvement project, one single centre observational and four review articles. Two articles originated from Japan and one article from the UK, Norway, USA, Spain, Sweden, Switzerland, Taiwan, Australia, Italy, Netherlands, Saudi Arabia, and France.

Five themes were identified from the literature as impacting a pwMND's oral health: dental status and oral hygiene activities, orofacial function, secretion management, service delivery and OHRQoL, as shown in table 1 (Supplementary file 2).

Themes Impacting Oral Health of pwMND

Dental Status and Oral Hygiene Activities

Five studies (four cross-sectional, one literature review) examined the dental status of pwMND, identifying issues relating to poor oral health, and the ability to carry out oral hygiene independently or with assistance. One study suggested assessed functional status and oral health status through recording tongue coating, presence of plaque, calculus and gingival inflammation.¹⁷ All participants with Amyotrophic Lateral Sclerosis (ALS) (n=37) examined demonstrated reduced oral health status, including increased plaque deposits, presence of gingival inflammation and calculus.

One single centre observational study examined the dental status and orofacial function of patients hospitalised with ALS (n=50), which identified increased incidence of tongue anomalies, tongue coating and calculus deposits.¹⁸ No increase in periodontal disease was identified.

Conversely, one study concluded oral health was not affected in MND.¹⁹ In this study, participants (n=23 limb onset, n=10 bulbar onset) attending an MND clinic in a hospital setting completed a self-reporting questionnaire into dental experience, current oral hygiene practices and diet. Clinical examination of their dentition, caries and periodontal status identified that oral hygiene was not significantly affected and participants appeared motivated to complete oral hygiene activities.

The ability of pwMND to carry out oral hygiene activities, together with their dental status was assessed in one cross-sectional study.²⁰ An online survey assessed the needs and barriers of pwMND, and their caregivers (patients n=259, caregivers n=43). Almost half reported they would like more support from dental professionals and 20% were not satisfied by the oral care conducted by themselves or their caregivers and 72% responded they were not informed about the importance of maintaining good oral health by their MND team. No clinical examination was carried out to directly assess their oral hygiene.

Four papers described the challenges of carrying out oral hygiene activities independently, due to reduced manual dexterity, highlighting the need for assistance.^{17,20,21,22} One paper explored available oral hygiene aids recommended for assisting with oral hygiene, including cheek retractors, dental shields for bite support, tongue scrapers and oral swabs, which was reported an improvement in the ability to carry out OH.²¹

Orofacial Function

Nine studies described how MND impacts orofacial function for pwMND, which included swallowing difficulties, masticatory difficulties, tongue abnormalities, reduced mouth opening and low muscle strength. It has been highlighted that reduction in mouth opening and jaw movement can impede access for good oral hygiene as well as impacting nutrition.²³

Three studies identified difficulties with swallowing in pwMND, particularly those with bulbar onset who were found to have more severe swallowing difficulties.²³ Increasing orofacial muscle weakness leads to dysfunction in the oral phase of swallowing,²² with one study reporting 87.5% had difficulties with chewing and swallowing.²¹ Impact of a reduced swallow was also reported to impact the pwMND's ability to take oral nutrition.²⁴ This may increase the need for high sugar nutritional drinks.

Five studies reported tongue abnormalities in pwMND. Two studies reported reduction in tongue movement as well as muscular atrophy of the tongue in pwMND.^{22,25} A literature review found that of 153 people identified with lingual fasciculations, 91% had a primary diagnosis of ALS.²⁶ Lingual fasciculation's were found to be associated with impaired swallowing and speech.

Two studies highlighted similarities between early symptoms of MND and temporomandibular dysfunction, including reduced bite force, limited mouth opening, tightness and stiffness of muscles.^{27,28} Symptoms were more likely to present in people with bulbar onset MND and was noted to be linked to food retention, oral self-injury and increased caries risk.²⁵

Secretion Management

Five studies were identified which explored aspects of secretion management.^{18,21,23,29,30} These studies reported pwMND being at increased risk of sialorrhoea, with excessive saliva build up leading to drooling in up to 88% of pwMND.²¹ This had a bidirectional effect with drooling was found to have a negative impact by increasing their risk of angular cheilitis, calculus build up and causing difficulty with functional and increasing their risk of dysphagia and aspiration. However it should be noted that saliva has a protective effect acting as a buffer to reduce caries risk.

Service Delivery

Two papers highlighted the challenges experienced by pwMND in accessing dental services due to physical disability or fear of aspirating.^{19,21} Only one study looked into the importance of oral health in the multidisciplinary management of pwMND.¹⁷ The study was carried out in an ALS tertiary centre, and aimed to be the first study that focused on the impact of oral health on functional status in the context of a multidisciplinary care approach.

There was no specific mention of the involvement of the dental team as part of the MDT, however it reported that adequate oral health care should be considered crucial in the multidisciplinary management of pwMND.

The Impact of Oral Health on Quality of Life

There was little research on the impact of oral health on quality of life. Only one study exploring the OHRQoL of pwMND, utilising the non-disease specific Oral health-related

Assessment Index (GOHAI-NL) and quality of life with the disease specific Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-5).²⁰ A weak positive correlation between self-reported severity of the disease and OHRQoL was identified. Participants experiencing barriers in seeking help with oral hygiene and oral health assessment experienced significantly lower OHRQoL, highlighting the importance of good oral health. There were no additional papers which explored the importance of oral health or what symptoms or outcomes mattered most to pwMND or their caregivers.

Participant involvement within research

As part of the scoping review, the participant involvement of pwMND within research studies was assessed to identify whether they were seen as either subjects of research, or as active participants within the process (supplementary file 1). Of the 14 articles included in the final review, none included the active involvement of participants, with the perspectives of pwMND included from the outset, or involvement in project design.

Stakeholder consultation

The findings of the scoping review and gaps identified in the literature were discussed with stakeholders from The Sheffield Better Outcomes in MND Patient and Public Involvement Group, which included pwMND and partners in care(n=5), MND related clinicians and researchers (n=10). This involved a group discussion where pwMND, as well as their caregivers were given the opportunity to participate.

PwMND reported mixed experiences with accessing dental care, with some maintaining regular reviews, or receiving care in a home setting, as they could no longer access the dental clinic. Others reported issues including lack of wheelchair access or reduced awareness by dental teams of the impact MND can have, including having the mouth open for a long time causing spasms.

PwMND were surprised that some studies found no impact on oral health. Challenges they reported in maintaining oral health included the need for assistance from carers who may have limited experience about how to clean teeth. Many reported reduced ability to carry out oral hygiene activities due to hand weakness, with some highlighting the impact this had for them in social situations. One individual with bulbar onset MND reported that motor symptoms meant they had issues with control of their tongue, leading to tongue biting and ulcers.

The stakeholders (whole group consulted) identified additional gaps including:

- Prevention of oral trauma
- Provision of restorative and prosthodontic dentistry - what works well and when
- Managing challenges with mouth opening, spasms, and gag reflexes
- Supporting and educating caregivers of those with MND

A key area that participants felt could be improved was service availability and dental professional expertise about treating pwMND. Priorities for future oral health research suggested by contributors included education of dental care professional's about the impact of MND and inclusion in undergraduate training. In addition, inclusion of dental teams within the MDT, and raising awareness of the importance of oral health with pwMND.

Discussion

This scoping review summarised the current literature on the oral health of pwMND, the effects on OHRQoL and identified potential areas for future research. The review identified that oral health appears to be negatively impacted in pwMND, partly due to impaired ability to perform oral hygiene activities and altered orofacial functioning. This was supported by the stakeholder consultation, who also reported barriers with accessing dental services.

The importance of good oral hygiene was highlighted in the literature. However, little was said about the progression of MND and the influence of poor oral health on other health outcomes, such as dysphagia and aspiration pneumonia. There have been multiple studies related to other health conditions, reporting the link between poor oral hygiene leading to the colonisation of oropharyngeal bacteria, and increased risk of aspiration pneumonia. It has been reported that the importance of good oral and denture hygiene was one of the key interventions to reduce the risk of aspiration pneumonia.^{13, 31, 32} More research could be carried out on the impact of poor oral health in the risk of aspirational pneumonia in pwMND.

No studies included addressed the ability of pwMND or their caregivers to carry out self-management of oral hygiene activities. There was limited acknowledgement of the influence of non-motor symptoms, such as declining cognition, on the ability to maintain oral health. Feedback from the consultation was that more emphasis was needed on the importance of oral health education, for both pMND and caregivers. Further research could look into expanding oral health education services to pwMND in a primary care or hospital setting.

The review identified limited assessment of OHRQoL in pwMND, with only one study carrying out a formal assessment which revealed a weak positive correlation.²⁰ Although overall the evidence suggests that MND negatively impacts the ability to receive oral care, one study reported that oral health was not affected by MND.¹⁹ It should be noted that participants in this study received specialist inpatient palliative and neurological care, with regular input from staff to support oral hygiene practices, which stakeholders agreed was not in keeping with their own experience. During the stakeholder consultation it was reported that oral health did impact daily life, with key issues being the ability to carry out oral hygiene independently and the impact of MND on oromuscular control and the ability to access dental care. The impact on MND on oral health may not impact all pwMND with same, depending on if they have limb or bulbar onset, dysphagia, require ventilation, and the level of support they receive. It was felt that further research is needed into the impact on quality of life focusing on different subgroups of pwMND in different settings.

From the grey literature, NICE guidance on MND management makes reference to oral health, suggesting the need for oral health assessment during initial diagnosis stages to ensure a prevention and management plan is in place.³³ The MNDA published guidance for the dental team highlights how symptoms of MND can make provision of mouth care more challenging.³⁴ A preventative approach together with developing a treatment plan at an early stage to minimise the risk of oral health problems is advised. The inclusion of a dental professional within the MND multidisciplinary team is recommended which was not reported in detail in any of the papers from the literature review. These provide useful guidance to dental professionals about managing pwMND, however more research is needed into the impact on OHRQoL.

The main strengths of this review include the use of a broad search strategy and inclusion of a stakeholder consultation stage, which added valuable insights unavailable from the published evidence alone. Although case reports were reviewed to uncover further barriers to oral health as well as management strategies, they were not included in the inclusion criteria. As only 14 articles met the inclusion criteria, this limited the amount of evidence reviewed. The majority of papers were cross-sectional studies or review articles, with no intervention studies. Only two studies included the use of healthy controls to allow for comparison. No qualitative data was identified. Generally, sample sizes were small, although two studies included over 100 participants, so it was difficult to assess potential issues over a wide population.

Access to dental care was one of the key issues reported at the stakeholder consultation, with many agreeing that inclusion of the dental team as part of the MDT would improve issues with access and early diagnosis. Dentists may play a role in

highlighting the potential diagnosis of MND in patients presenting with progressive dysphagia or jaw related symptoms, particularly in the presence of other neurological symptoms such as speech disturbance, allowing quicker referral. However, limited information was identified on dental service design for pwMND and how best to include oral health assessment as part of management pathways. Another limitation was that dental professionals were not involved in the stakeholder consultation to voice their experiences and potential service challenges when managing pwMND, as well as how their skills may benefit the MDT process.

Future research

Research is needed into the impact of oral health on MND outcomes, including quality of life, oral functioning (eating and swallowing), aspiration pneumonia and death. Interactions between oral health and treatment outcomes for different interventions to manage problems such as dysphagia and excessive oropharyngeal secretions is also a key area of interest. More research is needed to develop and validate disease specific oral health-related quality of life assessments which can successfully capture these outcomes. How dental care is best provided within the multidisciplinary MND care team remains uncertain.

The stakeholder consultation highlighted the need for further research into improving access to oral care as well as knowledge of the dental professional into the impact of MND on oral health and dental management. It should be noted that dental professionals were not part of the stakeholder group and this is another area that should be explored. Undertaking qualitative research will support in better understanding the experiences and perspectives of pwMND and their caregivers. Continuing involvement of pwMND in research will ensure that the development of interventions to improve oral health and caregiver education, or the design of new system pathways to improve access to oral care, leading to better outcomes.

Conclusion

This scoping review summarises the research available on the impact of MND on oral health and highlights gaps in current research. Oral health is an under-researched area in MND care, despite its potentially significant impacts on quality of life, general health and wellbeing. Research is urgently needed to address highlighted challenges with maintaining oral health, and how best to improve access to dental care.

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Declaration of interest statement

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