

# Oral hygiene in patients with motor neuron disease requires attention: A cross-sectional survey study

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## Abstract

**Aims:** Motor Neuron Disease (MND) is a progressive neurodegenerative neuromuscular disease, which can progressively impair arm-hand function. Needs and barriers of MND patients and their caregivers in performing oral hygiene were studied.

**Methods:** An online survey was sent to 706 MND patients. The questions of the survey included self-reliance, self-reported oral health, and oral hygiene. The oral health-related quality of life (GOHAI-NL) and the subjective well-being (ALSAQ-5) were also measured.

**Results:** A total of 259 patients responded (36.7%), of which 71.9% stated not to be informed about the importance of maintaining good oral health by their MND treatment team. Moreover, 40.4% would like to receive help concerning oral hygiene from a dental professional. 19.8% were not satisfied about oral care as conducted by themselves or their caregivers. Patients who do not ask for support with their daily oral care had a significantly worse oral health-related quality of life compared to patients who do ask for support.

**Conclusions:** The support for daily oral hygiene of MND patients and their barriers to requesting support needs more attention from both MND-treatment teams and general dental professionals.

## KEYWORDS

Amyotrophic Lateral Sclerosis (ALS), caregivers, dental care, Motor Neuron Disease (MND), oral hygiene, quality of life

## 1 | INTRODUCTION

Motor Neuron Disease (MND) is a neurodegenerative disease affecting the motor neurons, leading to severe disability and premature death. The lower motor neurons (LMN) or peripheral neurons extend from the spinal cord to the muscles. The upper motor neurons (UMN) or central

motor neurons are located in the cerebral cortex and brainstem. Loss of LMN results in muscle weakness, wasting, cramps, and fasciculation. Loss of UMN leads to spasticity, clumsiness, brisk reflexes, and functional limitations.<sup>1</sup>

In the Netherlands, the following classification of four different presentations of MND is used: Amyotrophic Lateral Sclerosis (ALS) with involvement of the UMN

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and LMN, Primary Lateral Sclerosis (PLS) with only UMN involvement, Progressive Spinal Muscular Atrophy (PSMA) with only LMN involvement and Progressive Bulbar Palsy (PBP) presenting with difficulties in the mouth and throat area with a possibility to transition to ALS.<sup>2,3</sup> ALS is the most commonly found form of MND worldwide. The prevalence of ALS varies strongly per ethnic subgroup and varies between 0.2 and 4.2 per 100 000 worldwide.<sup>4</sup> The median survival of patients with ALS is 2–3 years.<sup>1</sup>

Oral problems and difficulties in maintaining good oral health are commonly determined in patients with ALS.<sup>5</sup> When function of arms and hands is strongly impaired, patients will experience difficulties performing adequate oral hygiene themselves and will become dependent on caregivers. In case caregivers have no adequate skills in providing proper oral hygiene, this can result in suboptimal oral hygiene, causing a decreased oral health.

MND patients can also develop oral abnormalities as a result of the disease: dysphagia, dyspnea, poor cough, dysarthria,<sup>6</sup> sialorrhea,<sup>7</sup> thickened saliva,<sup>6</sup> black hairy tongue,<sup>8</sup> macroglossia,<sup>9</sup> and mouth opening limitation.<sup>10</sup> So far, no reports have been published on the impact of oral health-related quality of life of MND patients. In addition, there is a lack of knowledge on how MND patients perform their daily oral health routine. Therefore, the main objective of this study was to identify the needs and barriers of MND patients and their caregivers when performing daily oral care. Furthermore, this study aimed to assess the influence of self-perceived oral health and severity of the disease on the self-reported quality of life in patients with MND.

## 2 | MATERIALS AND METHODS

### 2.1 | Study design

This study was designed as a cross-sectional survey study among all registered MND patients in the Netherlands. The study was conducted between June and September 2019. Potential participants were informed about the study via an email newsletter of the Dutch ALS Centre. This email was sent to all 706 patients who were registered in the Prospective ALS study Netherlands Database.<sup>11</sup> Patients were asked to forward the newsletter email to their caregivers. When patients or their caregivers considered participation, they could click on a link to receive information about the study. After 6 weeks, a newsletter with the same information was sent as a reminder. Informed consent was obtained from the patient and caregivers at the start of the digital survey. Patients and caregivers did not receive any compensation for participation. The study protocol was approved by the Internal Review Board of the

Academic Centre of Dentistry Amsterdam (reference number 201916). The study was conducted in accordance with the principles of the 64th WMA Declaration of Helsinki (October 2013, Brazil). The Dutch law concerning Medical Research Involving Human Subject Act (WMO) does not apply to this study.

### 2.2 | Study population

Patients with a diagnosis of ALS, PLS, PSMA, and/or PBP were included in this study, as well as their caregivers. Both patients and caregivers had to be able to read and understand the Dutch language. Patients and caregivers were excluded if under the age of 18 years.

### 2.3 | Data collection

The survey was conducted digitally via the online forms management system Formdesk (Innovero Software Solutions B.V., Wassenaar, The Netherlands). All data was collected anonymously. Two separate surveys were used: one for the patients and one for the caregivers. For privacy reasons, the surveys of the patients and their caregivers were not associated. The surveys included demographic information, information about the MND diagnosis, self-reliance, oral situation (dentate or edentate, subjective sialorrhea or xerostomia, subjective mouth opening limitations, gingival bleeding, and foetor ex ore), oral hygiene and dental visits, and questions about the needs and wishes regarding help by a dental professional. Validated questionnaires were added to the survey concerning the oral health related quality of life (Geriatric Oral Health Assessment Index (GOHAI-NL))<sup>12</sup> and on subjective well-being of MND patients (Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-5)).<sup>13</sup>

### 2.4 | Data analysis

The GOHAI-NL questionnaire contains 12 questions with a 5-point-Likert scale. To analyze the impact of oral health-related quality of life, the GOHAI simple count score (GOHAI-SC) was calculated. This simple count score indicates if there is an impairment by combining all items with response “never” or “seldom” to a score 0 and the items “sometimes”, “often” and “always or nearly always” to a score 1. This results in the simple count score, ranging from 0 to 12. Item scores for questions 3, 5, and 7 were recoded resulting in a uniform direction of the scored items.<sup>12</sup> A lower GOHAI score indicates a better oral health-related quality of life. The ALSAQ-5 questionnaire

contains five questions with a 5-point-Likert scale. For scoring the subjective well-being, a similar simple count scoring system was used (ALSAQ-5-SC) as for the GOHAI. A high ALSAQ-5 score indicates a severe disability to the MND-related limitations. Both the ALSAQ-5-SC and the separate item from this questionnaire concerning arm-hand function were correlated with GOHAI-SC using a Spearman correlation test ( $r_s$ ). The Mann-Whitney U-test ( $U$ ), Kruskal Wallis test ( $H$ ), Independent samples t-test ( $t$ ), and Chi-squared test ( $\chi^2$ ) were used to compare groups. The data were analyzed using SPSS Statistics (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY, USA). The level of significance was set at 0.05.

### 3 | RESULTS

A total of 259 patients (response rate 36.7%) provided informed consent and completed the survey (mean age 64.3 years  $\pm$  10.6, range 26–86), of which 35.9% were female. A total of 43 caregivers provided informed consent and completed the survey, of which 86% were female. The mean age of the caregivers was 58.1 years ( $\pm$  13.6, range 25–83), 65.1% were partners of the patients and 34.9% were professional caregivers.

The time since diagnosis differed from less than 1 year ago (25.0%), to 1–3 years ago (32.4%) up to more than 3 years ago (42.5%). From all participants, 61.6% were diagnosed with ALS, 15.1% with PSMA, 21.3% with PLS, and 2.0% with a combination of ALS and PSMA or PLS. No patients with PBP participated in this study. The following results will not distinguish between these groups because no significant difference in severity of disease (ALSAQ-5-SC) was found.

More than two third of the patients (71.8%) indicated that they were never informed about the importance of maintaining good oral health by their MND-treatment team. Three-quarter of the patients visited a regular dental practice after being diagnosed with MND (74.9%,  $n = 194$ ) while 15.8% ( $n = 41$ ) did not visit a dentist at all. In addition, 6.9% ( $n = 18$ ) visited a center for special dental care and 1.9% ( $n = 5$ ) visited both their regular dental practice and a center for special dental care (missing = 1).

#### 3.1 | Oral health-related quality of life

The mean score for the severity of the disease (ALSAQ-5-SC) was 2.95 ( $\pm$  1.43). The mean score for the oral health-related quality of life (GOHAI-SC) was 2.22 ( $\pm$  2.17). A weak, positive correlation was found between the ALSAQ-5-SC and the GOHAI-SC ( $r_s = 0.34$ ,  $p < .001$ ). There was no correlation between the arm hand function (item 2 of

TABLE 1 Need for support from a dental professional

	Would you like to receive support from a dental professional regarding your oral health care?		
	No	Yes	Total
Patients performing their own daily oral care	127	76	203
Patients partially performing their own daily oral care and receive help	12	9	21
Patients receiving help regarding their daily oral care	14	19	33
Patients who are satisfied about their daily oral care	139	67	206
Patients who are not satisfied about their daily oral care	14	37	51

Missing = 2.

the ALSAQ-5) and the GOHAI-SC ( $r_s = 0.049$ ,  $p = .43$ ). Patients who do not ask for help with their daily oral care, because they find it too difficult to ask this, had a significantly higher GOHAI-SC compared to patients who feel the same but do ask for help with their daily oral care (mean 4.59,  $\pm$  2.61 resp. 1.27,  $\pm$  1.68;  $H(2) = 31.58$ ,  $p < .001$ ).

#### 3.2 | Need for support and satisfaction with daily oral care

A total of 104 patients (40.5%) indicated that they would like to receive support regarding their daily oral care from a dental professional. Patients who were fully dependent on others regarding daily oral care did not report more often a requirement for help from a dental professional compared to patients who performed their own daily oral care ( $\chi^2(2) = 4.82$ ,  $p = .089$ , Table 1). However, patients who were not satisfied about their daily oral care did desire to receive support from a dental professional significantly more often than satisfied patients ( $\chi^2(1) = 27.18$ ,  $p < .001$ , OR 5.5 95% CI 2.8–10.8) (Table 1). Patients who were able to perform their own daily oral care were more satisfied about their oral hygiene in comparison to patients who were dependent on others ( $\chi^2(2) = 8.52$ ,  $p = .014$ ).

A total of 51 patients (19.7%) responded that they were not satisfied about the way their daily oral care is conducted by themselves or their caregivers (Table 2). These dissatisfied patients received significantly more help with their daily oral care ( $n = 51$ , of which 18 receive help) compared to the satisfied patients ( $n = 208$ , of which 36 receive help;  $\chi^2(1) = 8.03$ ,  $p = .005$ , OR 2.6 95%CI 1.3–5.1). When patients experienced difficulty asking help, they were significantly less satisfied with their daily oral care

**TABLE 2** Arm-hand function and daily oral care

	ALSAQ-5 Q2 SC score <sup>a</sup> (range 0–1)		
	N	Mean	SD
Patients performing their own daily oral care	205	0.65	0.48
Patients partially performing their own daily oral care and receiving help as well	21	0.95	0.22
Patients receiving help regarding their daily oral care	33	0.97	0.17
Patients who are satisfied about their daily oral care	208	0.67	0.47
Patients who are not satisfied about their daily oral care	51	0.90	0.30

Missing = 0.

<sup>a</sup>Amyotrophic Lateral Sclerosis Assessment Questionnaire Question 2 Simple Count Score; A higher ALSAQ-5 Q2 SC score indicates more impairment of arm-hand function.

( $\chi^2(1) = 6.38, p = .012, OR 3.0$  95%CI 1.3–7.2). From all dissatisfied patients, 73% would like to get help from a dental professional regarding their oral hygiene.

Patients who were not satisfied about their daily oral care had significantly more difficulty in using their arms and hands (ALSAQ-5 Q2 SC score;  $U = 4064, p = .001$ ) compared to satisfied patients (Table 2) and they also received significantly more frequent help with their daily activities ( $\chi^2(1) = 12.85, p < .001, OR 3.3$  95%CI 1.7–6.4) compared to satisfied patients. Patients receiving help performing their daily oral care had significantly more difficulty in using arms and hands ( $H(2) = 20.59, p < .001$ ; Table 2). A total of 129 patients (64% of patients performing their own daily oral care) had a deteriorated arm-hand function (ALSAQ-5 Q2 SC score of 1), but performed their own oral hygiene. From these patients, 64 patients stated to have difficulty in using arms and hand “often” or “very often” or “always”.

Patients who would like to receive help from a dental professional had a significantly higher ALSAQ-5 SC score ( $t(255) = 4.90, p < .001$ ). Patients who were dissatisfied about their daily oral care had a significantly higher ALSAQ-5 SC score ( $t(257) = 5.84, p < .001$ ; Table 3).

### 3.3 | Barriers and needs by caregivers in providing daily oral care

Of all caregivers, 34.9% ( $n = 15$ ) declared difficulty in performing the daily oral care for the patient. Nearly half of the caregivers (48.8%,  $n = 21$ ) would like to receive instructions from a dental professional about how to perform daily oral care for someone else. However, most caregivers (72.1%,  $n = 31$ ) desired more information about daily oral

**TABLE 3** Severity of disease and need for oral care

	ALSAQ-5 SC score <sup>a</sup> (range 0–1)		
	N	Mean	SD
Patients who would like to get help from a dental professional <sup>†</sup>	104	3.47	1.34
Patients who would not like to get help from a dental professional <sup>†</sup>	153	2.62	1.39
Patients who are satisfied about their daily oral care <sup>+</sup>	208	2.71	1.40
Patients who are not satisfied about their daily oral care <sup>+</sup>	51	3.94	1.14

<sup>\*</sup>Missing = 2, <sup>†</sup>missing = 0.

<sup>a</sup>Amyotrophic Lateral Sclerosis Assessment Questionnaire Simple Count Score; A higher ALSAQ-5 score indicates more impairment.

care through a flyer or letter, or would like to receive a training (39.5%,  $n = 17$ ). Professional caregivers and non-professional caregivers (e.g., partners) did not differ in their need to receive instructions from a dental professional, need for information by flyer or letter, or need for training ( $\chi^2$  tests, all  $p > .05$ ). In addition, there was no difference between both groups with respect to experiencing problems in providing daily oral care ( $\chi^2(1) = 0.27, p > .05$ ).

## 4 | DISCUSSION

This is the first study assessing the needs and barriers of MND patients and their caregivers regarding daily oral care and investigating the influence of self-perceived oral health and severity of the disease on oral health-related quality of life (OHRQoL). Until now, the oral health in these patients has been studied, but not in relation to their OHRQoL. For MND patients, it has been suggested that it is important to assess the patients' priority for daily oral care and oral health care in order to prevent overtreatment and burdening these patients unnecessarily and thereby respecting their autonomy.<sup>14</sup> However, the current results show that oral health is important for these patients and there is a need for support for daily oral care in this patient group, both on a daily basis by caregivers or partners and support by dental professionals. Most patients in this study visited a dental practice regularly and one should expect that this support is provided already. A possible explanation of this apparent contradiction could be that the knowledge on MND of regular dentists in the Netherlands is insufficient, especially in supporting the patient and his/her caregivers with regard to the daily oral hygiene. Therefore, these dentists might be unable to match the needs of these patients.

Almost half of all MND patients in this study reported that they would like to receive support from a dental pro-

professional regarding their daily oral care. Patients with a high disability, patients who are completely dependent on others, and patients who are not satisfied about their daily oral care would like to receive more often support from a dental professional. Only a weak positive correlation was found between the self-reported severity of the disease and the OHRQoL. However, the patients who did not ask for support with their daily oral care because they experience a barrier asking for help, had a significantly lower OHRQoL.

The OHRQoL questionnaire is a subjective tool to assess a patient's perception of oral health, and is often measured using the Oral Health Impact Profile (OHIP) questionnaire.<sup>15</sup> Since the GOHAI questionnaire is designed for care-dependent and care-independent elderly people, and does not include questions specifically on elderly, this validated questionnaire was found to be appropriate for this study. Several studies showed that minor deteriorations in the OHRQoL can be detected by the GOHAI-questionnaire in elderly and care dependent people, compared to the more frequently used OHIP-questionnaire which is better in detecting severe impacts.<sup>12,16,17</sup>

MND patients who had difficulties in requesting help and, therefore, did not ask for help regarding their daily oral care, reported a significantly higher GOHAI score. This suggests that a lack of (social) support negatively influences the OHRQoL, which is in line with previous studies in other populations.<sup>18</sup> A higher GOHAI score in care-dependent people cannot be simply explained by oral health factors and general health factors, since social support, income, and education level are also associated with GOHAI outcomes.<sup>18</sup> This can explain why no correlation was found between arm-hand function and OHRQoL. A low mean GOHAI score as found in this study indicates that care-dependent people cope with increasing impairments and adapt to oral discomfort, such as difficulty in eating and speech, decreased esthetics and pain.<sup>19</sup>

More than half of all dissatisfied patients in the present study performed the daily oral care themselves. However, patients who performed their own oral hygiene often had an impairment in arm-hand function. In fact, more than half of these patients had difficulties in using their arms and hands often, very often or always. Since it is known that dexterity of the hands is associated with the ability to perform effective daily oral care, it can be assumed that the quality of daily oral care has become insufficient due to this impairment.<sup>20–22</sup> A need for autonomy and the wish not to burden their caregivers will play a role in the barrier experienced when support is needed.<sup>23,24</sup> It has been reported that this rejection of support can cause stress among caregivers.<sup>23–25</sup>

Actively offering support with daily oral care by both caregivers and professionals can increase oral hygiene

behavior.<sup>26</sup> Previous research showed that actively offering help and appropriate support can positively influence and maintain a positive attitude and independence of patients with ALS.<sup>24</sup> Support becomes more important with increasing disease severity. Providing support on oral hygiene can improve the effectiveness of the daily oral hygiene, and therefore improve oral health.<sup>25</sup> In order to study the barriers and needs in the different phases of the disease in more detail, qualitative research could be performed in order to assess the needs of the caregivers for providing daily oral care in an effective way.

The current study showed that a significant part of MND patients were not satisfied about their daily oral care. The barriers encountered by patients who ask for help from their caregivers and dental professionals with this part of daily routine needs attention. In the Netherlands, MND patients are in frequent contact with a multidisciplinary treatment team. Therefore, integrating oral care into these multidisciplinary teams should help MND patients improve their oral health.<sup>27,28</sup> Concurrently, general dental professionals should be more aware of this vulnerable patient group, and act proactively towards the progressing nature of the disease.

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