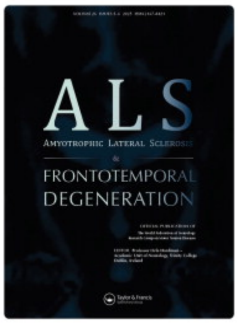
Article:

Musson, L.S., Baxter, S.K., Norman, P. et al. (7 more authors) (2025) Perceptions of healthcare professionals on optimal delivery of noninvasive ventilation care to people living with motor neuron disease. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. ISSN: 2167-8421

https://doi.org/10.1080/21678421.2025.2539896



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Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration

ISSN: 2167-8421 (Print) 2167-9223 (Online) Journal homepage: www.tandfonline.com/journals/iafd20

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To cite this article: Lucy S Musson, Susan K Baxter, Paul Norman, David O'Brien, Mark Elliott, Stephen Bianchi, Georgios Kaltsakas, Christopher J Mcdermott, Esther V Hobson & Theocharis Stavroulakis (22 Aug 2025): Perceptions of healthcare professionals on optimal delivery of noninvasive ventilation care to people living with motor neuron disease, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, DOI: 10.1080/21678421.2025.2539896

To link to this article: https://doi.org/10.1080/21678421.2025.2539896

Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2025; 0: 1–8

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RESEARCH ARTICLE

Perceptions of healthcare professionals on optimal delivery of noninvasive ventilation care to people living with motor neuron disease

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Abstract
Background: Patients with motor neuron disease (MND) often do not experience the full survival and quality of life benefits of noninvasive ventilation (NIV). Successful delivery of NIV is challenging to multiple healthcare professionals involved in the respiratory care patient journey and considering their perspectives is crucial in order to understand how to deliver optimal care. *Objective:* To identify the factors that influence NIV delivery in MND from a healthcare professional perspective and understand how obstacles can be overcome to optimize care. *Methods:* Qualitative focus group discussions with healthcare professionals delivering respiratory care and support to MND patients in the UK and charity representatives. *Results:* Thirty healthcare professionals and three charity representatives participated in five focus groups. A range of factors that influence the delivery of NIV across the entire respiratory care pathway were identified. These were grouped under four main themes: multidisciplinary working; NIV service structure; professional further education and training; and good use of NIV and effective ventilation. *Conclusions:* There is a need for specific resources to support service delivery; frequent, funded, and structured training to support healthcare professionals to deliver good care; as well as ways to encourage optimal staff practice so patients get the best care.

Keywords: *motor neuron disease, amyotrophic lateral sclerosis, mixed methods, thematic analysis, noninvasive ventilation, respiratory care*

Introduction

Motor neuron disease (MND) is a fatal condition, typically leading to respiratory failure and death within 2–3 years (1). There are limited pharmacological treatments for MND, but noninvasive ventilation (NIV) can significantly improve survival and quality of life (2–4). Effective NIV use requires both patient adherence and proper machine ventilation delivery (5,6). NIV is a complex intervention; its success depends on various factors including service structure, healthcare professional (HCP) attitudes and how patients with MND, and their informal carers, use it (7). HCPs must work with patients, and their informal carers, to identify barriers throughout the respiratory care pathway, from diagnosis to end-of-life (5,6). Many patients struggle with NIV, preventing them from receiving

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/21678421.2025.2539896.

(Received 12 June 2025; revised 11 July 2025; accepted 22 July 2025)

ISSN 2167-8421 print/ISSN 2167-9223 online
DOI: 10.1080/21678421.2025.2539896

maximum benefit (8–10). Biopsychosocial factors, such as being female, older, living alone, and lower socioeconomic status predict reduced NIV use and survival (5,6).

Implementing NIV to overcome these barriers is challenging (5,6), with significant variability in individual HCP and service practices (11). While factors enabling success and examples of good practice have been identified (5,6,11) this study aims to clarify and confirm these findings and to explore HCP perceptions on optimizing NIV delivery, to ensure all patients receive maximum benefit.

Methods

A qualitative cross-sectional design was employed involving focus group discussions with HCPs providing respiratory support to patients with MND and charity representatives. This was the second part of a wider explanatory sequential mixed-methods study to develop an online information toolkit for HCP practice. The first part, a cross-sectional questionnaire survey of HCPs, explored individual staff and institutional practices across the respiratory care pathway (11).

The focus groups aimed to clarify, confirm, and contextualize the survey findings, and to further explore how to promote good clinical practice. Focus groups were chosen for their effectiveness in engaging professionals and facilitating discussion and exchange of perspectives in a collective context (12).

Participants were recruited from survey respondents who expressed interest in further research. The study was advertised on social media, professional group websites, and third-party stakeholders like the MND Association (11). A convenience sample ensured diverse service area sizes, professional backgrounds, and experience levels (13). Focus group locations were decided based on service locations identified in our preceding survey, allowing for differences in size, capacity, and expertise (11).

The focus groups were guided by the "What?", "So what?" and "Now what?" framework (14). The "What?" stage involves discussing what has happened so this part of the discussion focused on presenting the key survey findings (supplementary materials) (11). The "So what?" stage involves analyzing what had happened. Participants were encouraged to reflect on the survey findings in relation to their own experiences and clinical practice. The "Now what?" stage involves thinking about the future. During this final stage the discussion focussed on the barriers and facilitators to optimal practice. Participants also discussed ideas of future actions to be able translate our findings into improved delivery of NIV to plwMND. Earlier focus group discussions provided new ideas to discuss in the later focus groups. Two researchers with qualitative expertise in MND (15,16) co-facilitated the audio-recorded focus groups, which were transcribed verbatim. Thematic analysis was used to analyze the qualitative data (17). Two researchers independently analyzed the data using NVivo (v12.0) (18), with input from other team members. Emerging themes and discrepancies were discussed and resolved with the wider research team. Demographic data were descriptively summarized.

Ethical approval was obtained from the University of Sheffield Research Ethics Committee (Ref. 025512). Participants provided informed consent and the report adheres to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (19).

Results

Thirty-three participants attended five focus group discussions with between five and nine participants in each group, which took place between September and November 2019 (see Table 1). Discussions ranged from 106 minutes to 123 minutes and were held across England in Manchester, London, Birmingham, Bristol, and Leeds. Focus group participants had between 1 and 26 years' experience in MND care and their MND caseload ranged from 3 to 240.

Four overarching themes with twelve subthemes of factors influencing clinical practice emerged from the analysis (Table 2). A detailed list with illustrative quotations is provided in the supplementary material.

Theme 1: Multidisciplinary working

Shared and informed decision-making. Participants emphasized the importance of an individualized approach to NIV care and *respecting the patient's wishes. Effective communication from HCPs with expertise* in MND ventilation and *working in different specialities*, alongside *comprehensive discussions with patients, and their informal carers,* was key for shared and informed decision-making. This was thought to be achievable *through early discussions.* Participants also felt that providing information to patients and carers about all aspects of the disease including the pros and cons of NIV, through "*open honest discussion from the professional" (MND Nurse)* would help them make informed decisions and possibly improve the likelihood of patients using NIV. There was a consensus that this approach may help the *patient feel empowered* that it is their choice whether to use NIV. It was highlighted that it is important to *reassure* patients that they will continue receiving respiratory care even if they decide not to trial NIV or change their mind after initiation. There was a strong feeling

Table 1. A breakdown of professional characteristics of participants who attended each focus group.

	Pseudonym	Location	Job role	Speciality	Time spent providing MND respiratory care	Number of MND patients on caseload	Sees patients at home
Focus group 1	Respiratory physiotherapist	NHS trust	Physiotherapist	M/R	3–5 years	50–60	Yes
	MND association representative	MND association branch	MND Association Representative	M	N/A	N/A	N/A
	Respiratory nurse	NHS trust	Nurse	R	3–5 years	100–150	Yes
	Respiratory physiotherapist	NHS trust	Physiotherapist	M/R	5–10 years	50–100	Yes
	Respiratory consultant	NHS trust	Doctor (Consultant)	R	5–10 years	30–50	Yes
Focus group 2	Respiratory consultant	NHS trust	Doctor (Consultant)	R	5–10 years	50–100	No
	MND association representative	MND association branch	MND Association Representative	M/R/N/C/P	5–10 years	>200	Yes
	MND nurse	NHS trust	Nurse	M	5–10 years	50–100	Yes
	Palliative care physiotherapist	Hospice	Physiotherapist	R/P	>10 years	30–50	Yes
	Respiratory physiotherapist	NHS trust	Physiotherapist	R	1–3 years	50–100	Yes
	Respiratory Nurse	NHS trust	Nurse	R	<1 year	50–100	Yes
Focus group 3	Respiratory nurse	NHS trust	Nurse	R	5–10 years	<10	Yes
	Respiratory physiotherapist	NHS trust	Physiotherapist	R	5–10 years	50–100	Yes
	MND coordinator	NHS trust	MND coordinator	M	5–10 years	30–50	Yes
	Respiratory physiotherapist	NHS trust	Physiotherapist	R	1–3 years	3050	Yes
	Palliative care physiotherapist	NHS trust	Physiotherapist	M/P	5–10 years	10–30	Yes
	Community physiotherapist	NHS trust	Physiotherapist	C	>10 years	<10	Yes
Focus group 4	MND Nurse	Hospice	Nurse	M	>10 years	<10	Yes
	Respiratory nurse	NHS trust	Nurse (specialist ventilation)	R	1–3 years	50–100	Yes
	Palliative medicine doctor	Hospice	Speciality doctor	P	3–5 years	10–30	Yes
	Respiratory physiotherapist	NHS trust	Physiotherapist	R	5–10 years	Unknown	No
	Neurology nurse	NHS trust	Nurse (specialist)	M/N/C	>10 years	10–30	Yes
	Palliative medicine consultant	NHS trust	Doctor (Consultant)	P	3–5 years	Unknown	No
	Respiratory physiotherapist	NHS trust	Physiotherapist	R	5–10 years	<10	No
Focus group 5	Neurology community matron	NHS trust	Community matron	M/N/C	>10 years	<10	Yes
	Respiratory nurse	NHS trust	Nurse	R	>10 years	50–100	Yes
	Respiratory physiotherapist		Physiotherapist	M/R	>10 years	30–50	Yes
	Respiratory nurse	NHS trust	Nurse	R	>10 years	50–100	Yes
	MND association representative	MND association branch	MND Association Representative	M	5–10 years	N/A	No
	Respiratory nurse	NHS trust	Nurse	R	3–5 years	<10	No
	Neurology nurse	NHS trust	Nurse	M/N/C	5–10 years	10–30	Yes
	Respiratory nurse	NHS trust	Nurse	R	5–10 years	30–50	Yes
	Respiratory nurse	Unknown	Nurse	R	Unknown	Unknown	Yes

M: MND; R: Respiratory; N: Neurology; C: Community; P: Palliative care. Time spent providing care and number of patients on caseload are categorized into groups to maintain anonymity. Whilst the participants were numbered the quotes in the report are not numbered to further reduce the risk of any identification.

Table 2. Themes and Sub-themes of factors influencing the delivery of NIV care in MND.

Theme	Sub-themes
Multi-disciplinary working	Shared and informed decision-making Knowledge and understanding Bulbar function and oropharyngeal and respiratory secretion management Professional expertise and clinical judgment Carer bereavement support and counseling
NIV service structure	Service capability and capacity Ongoing support Modem and/or tele-monitoring
Professional further education and training	Professional conduct and confidence Ethics and legalities surrounding care (i.e. in the withdrawal of NIV)
Appropriate use of NIV and effective ventilation	Use of, and efficacy of, the ventilation Creating a protocol for NIV initiation and optimization

NIV: noninvasive ventilation.

toward *revisiting discussions* about NIV, as patient wishes may change, and ensuring that the care team are aware of these discussions. Participants spoke of the need for a *shared electronic record system* to support this. The *Motor Neuron Disease Association* charity was seen as helpful for facilitating difficult discussions because they have more time and can provide a different perspective to HCPs.

Knowledge and understanding. *Staff professional knowledge* and having a *holistic understanding* of MND and respiratory management were key contributors to improving NIV provision. HCP *procedural knowledge level* was seen as vital for providing an optimal service. This was perceived as key during NIV initiation as it requires specialist expertise and understanding of NIV settings. Professionals unfamiliar or less experienced during the withdrawal of NIV may often find it a difficult experience. Participants identified *challenges to training care agencies* as a barrier to improving the procedural knowledge needed to deliver NIV. Staff *resistance to change* was a key barrier to improving professional understanding and optimizing NIV service provision.

Patient and carer understanding about different disease management aspects, like pros and cons of NIV use was another contributing factor. Having *honest and comprehensive discussions* about NIV, having *support group meetings* available and giving *equipment demonstrations* were seen as helpful for improving patients' and carers' understanding of and preparation for future NIV use.

Bulbar function and oropharyngeal and respiratory secretion management. There was consensus that an *early airway clearance assessment* is an essential part of respiratory monitoring. There was consensus that *effective secretion management* is important to gain maximum NIV benefit. It was felt that a multidisciplinary approach can help with *rapid identification and treatment of excessive secretions* ensuring that patients get the *right medication and equipment.* Participants highlighted the importance of *tailored care* depending on individual problems with secretions. The c*omplexities in the process of medication prescription,* resulting in patients not receiving medication in a timely manner, was a barrier to this. For example, not all HCPs have the *authority to prescribe medication.* Additionally, participants noted that some general practitioners will *not prescribe certain medications* that are effective for secretion clearance in MND and some HCPs rely on their *professional personal preference* when choosing treatments. Participants also highlighted the importance of *weighing up the costs vs. benefits of providing cough augmentation* equipment as not all patients benefit from using such devices. Moreover, some services encounter problems with having *access to funding and staff to deliver Cough Assist* and there is a need for this complex intervention to be *provided by experts.* Participants also spoke of the need to provide *additional support to patients who are at high risk* of encountering problems (such as those with bulbar dysfunction) because they can still use NIV with appropriate support.

Professional expertise and clinical judgment. Participants spoke of the importance of bringing different expertise from a multi-disciplinary approach to *provide holistic MND care* and to optimize NIV. They also emphasized the importance of *clinical experience and judgment* and the need to make *balanced clinical decisions* between following guidelines and operating based on their own expertise. This was seen as particularly important when *identifying priorities* for a patient's care, especially when initiating NIV by choosing the NIV settings, and during the withdrawal of NIV. It was also seen as particularly important when dealing with a patient who reports no respiratory difficulties when their HCP is able to *recognize subtle deteriorating signs of respiratory dysfunction.* Nevertheless, the group raised concerns about staff being *resistant to change* their practice.

Carer bereavement support and counseling. Participants emphasized the need for *improvements to be made for post-bereavement support* because "*the carers are often missed out*" (Palliative Care Physiotherapist). Participants thought there is a need for more support to be provided and that *bereavement support should take place during the planning of end-of-life care* with *honest and open discussions* occurring with informal carers as well as the patient. *Local support groups* such as those offered by the MND Association charity were seen as useful for supporting patients and their family members during the end stages of the disease. The participants were also keen for professionals to *work closely with palliative care teams* to provide bereavement support but recognized that not all palliative care teams offer post-bereavement support.

Theme 2: NIV service structure

Service capability and capacity. Participants stressed the importance of services having the capacity and capability to manage care demands. Several barriers to providing effective care were related to availability and access to *resources such as staff, appointments, technology, equipment, and inpatient facilities.* Having appropriate *funding/commissioning* was seen as crucial and participants raised concerns that some services were not receiving necessary resources to the extent they were needed. Moreover, participants emphasized the need for HCPs to be able to *refer patients to other services and outreach teams* and funding is a key prerequisite for this. A key enabler to providing good care was having the ability to be *flexible* to manage unexpected issues and critical patients. In line with this, HCPs emphasized the importance of *advance care planning* as this is key for allowing NIV optimization to be achieved more quickly.

Ongoing support. *Monitoring patients using NIV frequently* was a key enabler to success and linked with building a good HCP-patient rapport. To facilitate building a good rapport participants agreed that the gold standard should be to provide both *face-to-face and remote support as well as having access to and/or the ability to see patients in a variety of locations* (e.g. in hospital and at home). *Considering the individual patient's needs and preferences* was seen as important during this monitoring stage. For example, *email and text* communication was described as useful for providing ongoing support for patients with dysarthria. *Home monitoring* was seen as useful for patients who did not want to or could not travel to hospital. All participants agreed that patients and their informal carers should be *given information about who they should contact* and how to contact them if they have any questions or concerns, particularly during *out of hours.* Participants also emphasized the need for services to ensure staff availability to answer/respond to these queries and *video calls* were seen as a helpful means for this. Moreover, improving *accessibility* to enable patients to attend clinics was perceived as key. For example, *providing transport and befrienders* for patients was seen as useful for helping patients to attend. *Drop-in sessions relating to troubleshooting mask/tube problems* were also seen as helpful.

Modem and/or tele-monitoring. Participants spoke positively about *utilising technology* to support patients. Tele-monitoring was seen as helpful for staff to be able to modify NIV settings remotely. However, some concerns were raised about the *cost implications* and staff *training complexities* associated with all patients being provided with machines capable of tele-monitoring. There were also concerns about remote monitoring *risking the patient-HCP relationship.*

Theme 3: Professional further education and training

Professional conduct and confidence. It was clear that participants recognized that "*some [clinical staff] are going to have far more specialist knowledge … and everyone's going to have their strengths in the team*" (Respiratory Physiotherapist). *Feeling a sense of responsibility* and exhibiting *leadership were* perceived as important, particularly during the withdrawal of NIV as participants thought that this helped all staff to feel supported under challenging circumstances.

Ethics and legalities surrounding care (i.e. in the withdrawal of NIV). Participants emphasized the importance of having *robust clinical guidance* for supporting HCPs to deliver good care. For the withdrawal of NIV, participants thought the Association for Palliative Medicine guidance (20) provided people the *reassurance* that in the UK, NIV withdrawal is ethical and legal, which *removes some of the fear.* While awareness of guidelines is key, some participants felt that some HCPs *do not agree with and*/or *choose not to follow guidelines.* Participants thought this was particularly the case for HCPs who *overly rely on their experience* and are *resistant to change.* Participants spoke of concerns about the ethics and legalities of withdrawing NIV for patients who have *cognitive problems* where *capacity may be a concern.*

Theme 4: Appropriate use of NIV and effective ventilation

Use of, and efficacy of, the ventilation. Participants recognized the need for ongoing *education and training* for staff as well as patients and family members to promote NIV use and effective ventilation. Many participants spoke of the need to *challenge people's negative views of NIV* as they thought some HCPs and patients may hold the belief *that the patient will become reliant on it* and, as a result, experience *anxiety and fear*. The participants voiced that there is a need to *manage these concerns* and work together with patients to ensure they benefit from NIV. Participants also expressed the importance of *proactive monitoring* which includes taking an individualized approach to recognize potential challenges. This included things like trialing different masks, changing settings, and managing secretions. *Involving expert professionals* from different specialities in troubleshooting is key for managing patients on NIV. Participants also recommended *gradual acclimatization* for patients struggling to use NIV or encouraging short-term use in the daytime before increasing use overnight.

Creating a protocol for NIV initiation and optimization.

When discussing the idea of creating a protocol for the initiation and optimisation of NIV, participants raised concerns about care *becoming too "protocolised"* and *"losing expertise"* (Respiratory Nurse). They thought a protocol with standardised initiation settings based on specific clinical characteristics would be *too rigid* as care should be *flexible and individualised*. Furthermore, they stressed concerns about a protocol for the acute initiation of NIV potentially being *dangerous*. They thought a *troubleshooting guide* might be helpful for patients, carers and less experienced HCPs to know what problems to look out for but believed assessing needs and carrying out alterations and interventions should be done by people with expertise.

Discussion

NIV is the only intervention improving both survival and quality of life in patients with MND (2), yet it remains underutilized (8–10). This study builds on previous work demonstrating extensive variation in NIV delivery across the UK (11). Various factors influencing NIV delivery and success, from a HCP perspective, were identified in the current study. A holistic, multidisciplinary approach addressing barriers throughout the respiratory care pathway appears to be key. For example, the neurology team may prepare patients physically and emotionally for NIV, with biopsychosocial support crucial during initiation and optimization. Interdisciplinary working is vital for certain patient groups, such as those with bulbar dysfunction, who require airway clearance equipment, secretion medication and psychological support. This may explain why attending a multidisciplinary clinic correlates with improved survival (21–23).

The ability to identify and address a wide range of intersectional barriers to NIV may augment the likelihood of success. For example, being aware of the need to improve information about NIV, particularly to patients living in rural areas (24), plus offering telemonitoring and home visits are also likely to improve use in underserved groups. Providing services by email and text may be of benefit but may widen inequalities for those lacking digital literacy or access to carers (25).

Specialist knowledge/experience were perceived to be vital to success for allowing HCPs to tailor approaches to problems. However, this may also hinder future service improvement, as resistance to change was a common theme, especially among experienced practitioners who might perceive challenges to their practices as a threat to their professional self-identity (26). Experience and seniority were also identified as facilitators to good practice, through leadership, education, developing coherence, and a shared sense of responsibility, which can lead to more effective implementation of change (27).

Strengths and limitations

Using a qualitative design allowed for an in-depth exploration of factors influencing NIV delivery in MND. Focus groups were conducted across different UK areas to ensure representation. While convenience sampling limits representativeness, participants were selected to reflect diverse backgrounds and experiences, allowing a broad spectrum of HCP views to be captured. Additionally, the focus groups confirmed several factors already identified from the survey (11). The focus groups were conducted before the COVID-19 pandemic, and MND care has since changed (28–31); therefore, it is important to acknowledge that factors influencing NIV delivery may differ before, during, and after the pandemic. Moreover, this study explored the factors that influence the delivery of NIV to plwMND in the UK. However, it is anticipated that many of these factors will be applicable to worldwide service delivery.

Future research

This research leaves unclear whether more formal guidance for NIV initiation and monitoring in MND would improve outcomes, and what that guidance would look like. This study makes it clear that any efforts to improve NIV success must consider the entire respiratory pathway, as well as the needs and behaviors of all involved; the MDT, patients, and their informal carers. Future work will involve drawing on the COM-B (Capability, Opportunity, Motivation, Behavior) and Theoretical Domains Framework models of behavior change to interpret identified barriers and enablers related to determinants specific to HCP behaviors (32–34).

This approach is particularly useful in designing effective interventions (35) and has been applied in MND (36). We have developed a free online toolkit reflecting available evidence and best practices in this research (www.niv4mnd.co.uk). However, our findings suggest this would only be accepted by HCPs if it allowed for flexibility and individualization to reflect the varied patient needs, local service contexts, and clinician judgment.

Conclusion

Our findings suggest a need for practice change to ensure good NIV delivery. Not only is there a need for adequate resources to ensure services can run at an optimal standard, but also to support HCPs to develop the necessary confidence and competencies for optimal care.

Acknowledgements

The authors are grateful to everyone who took part in the focus groups.

Declaration of interest

No potential conflict of interest was reported by the author(s).

Rights retention statement

Funding

The study was funded by a National Institute for Health Research10.13039/501100000272 (NIHR) programme grant for Research for Patient Benefit (PB-PG-1216-20041). CJM is supported by the NIHR Sheffield Biomedical Research Center10.13039/501100018835 and an NIHR Research Professor award (NIHR301648). LSM is supported by a My Name'5 Doddie Foundation Doctoral Fellowship (DOD/14/17) and CMD'S National Institute for Health Research10.13039/501100000272 (NIHR) Professorship (NIHR301648). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

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Data availability statement

Factors/themes identified with illustrative quotations from the transcripts are available in the supplementary material.

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