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Working with people living with motor neurone disease and the impact on professionals' emotional and psychological well-being: A scoping review

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Abstract

Background: Integrated multidisciplinary care is required to manage the progressive and debilitating symptoms associated with motor neurone disease. Professionals can find providing the level of care required by this population clinically and emotionally challenging. To support those working with these patients it is important to understand the experience of the entire multidisciplinary team involved and the impact of working with motor neurone disease on their emotional and psychological well-being.

Aim: To identify what is known about (1) healthcare professionals' experience of working with motor neurone disease and (2) the impact of this work on their emotional and psychological well-being.

Design: Scoping review. Review protocol registered on Open Science Framework.

Sources: Five electronic databases were searched in January 2023 and 2024. Grey literature and hand searches were completed.

Results: Fifty-one sources published between 1990 and 2023 were included. A total of 1692 healthcare professionals are represented. Three main categories were identified: (1) The demands of providing motor neurone disease care. (2) Factors influencing professionals' ability to provide desired levels of care. (3) The emotional impact of working with motor neurone disease. Subcategories are depicted within these.

Conclusion: Positive experiences included job satisfaction, enhanced perspective and receiving gratitude, while negative implications such as stress, emotional exhaustion and burnout also featured. The demands of motor neurone disease patient care, the organisation of services and resources required to meet patient and family needs and the emotional burden for professionals involved, warrant greater recognition in clinical practice, guidelines and future research.

Keywords

Psychological well-being, emotional distress, health personnel, occupational stress, multidisciplinary care team, neurology, palliative care, burnout, psychological

What was already known?

- Integrated multidisciplinary care, provided by an extensive multidisciplinary team is recommended to manage many progressive symptoms and to optimise quality of life for people living with motor neurone disease.
- Professionals can find providing the level of care required and interactions with these patients and families both clinically and emotionally challenging.
- Literature on the experience and impact of working with motor neurone disease from perspective of all healthcare professionals involved has not been systematically reviewed.

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What this paper adds?

- Motor neurone disease care can be experienced as intensive, distinctive and more time-sensitive than the care required by patients with other life limiting conditions.
- Professionals have experienced emotional exhaustion, burden, frustration, anxiety, stress and burnout due to caregiving for motor neurone disease patients and their families.
- The benefits of working with motor neurone disease are job satisfaction, receiving gratitude and enhanced appreciation for one's own personal life.
- External and organisational factors often perceived as outside of professionals control can limit their ability to provide desired levels of care, often resulting in feelings of stress and frustration.
- Multidisciplinary care is not only necessary to meet the multiple needs of patients and informal caregivers but is also an important source of emotional support for professionals working with motor neurone disease.

Implications for practice, theory, policy or future research?

- The emotional burden for professionals working with motor neurone disease patients and their families should be recognised. Future research should focus on directly addressing and measuring the psychological health and well-being of professionals involved in providing this care.
- The organisation of motor neurone disease patient services and processes for interservice communication and collaboration should be considered to reduce many of the external demands and associated stressors for professional care teams.
- Professionals working with motor neurone disease patients should have access to collegial and multidisciplinary team support, future work should consider what additional supports, interventions or training could help to reduce the professional stress and emotional toll associated with working with this complex condition.
- Future work should consider both the individual and shared needs for support of the different teams and professionals involved in providing motor neurone disease patient care.

Introduction

Motor neurone disease is a group of rapidly progressive neurodegenerative diseases,[1] of which amyotrophic lateral sclerosis is most prevalent. These terms are often used interchangeably, but in this review motor neurone disease will define the condition. Motor neurone disease is a terminal disease, with an average life expectancy of 1–4 years from diagnosis.[2] Current treatment focuses on managing associated symptoms and optimising quality of life,[3] using a multidisciplinary approach to care.[4–7] Multidisciplinary care should be delivered by a specialist team, in collaboration with community, hospital and palliative care services.[4–6]

Much of the research on the delivery of multidisciplinary care has focussed on the views, experiences and needs of patients and informal caregivers'.[8–10] Patients and informal carers recognise and value high quality multidisciplinary care.[11] However, they have experienced services as being fragmented,[12] encountered healthcare providers with limited knowledge and understanding of motor neurone disease symptoms,[9,13] received poorly communicated and conflicting information[14] and experienced difficulty accessing home care, respite, palliative care and specialist services.[8,9,15] As the disease progresses increasing dependency and the level of care required have also been associated with high levels of burden,[16] emotional distress[17] and reduced psychological well-being[18] for patients and informal caregivers. The physical and emotional strain of informal caregiving is recognised in best practice and clinical management guidelines.[4–7]

Informal caregivers provide most of the home-based care,[19] but depend on an integrated team of professionals for support with the patients and their own physical, psychological and social needs.[10,20] Despite the level of support and care provided by professional care teams, in often clinically and emotionally difficult circumstances, the impact of this work on the their own well-being has not been widely considered in research to date.[21] The New Zealand best practice recommendations are the only guideline briefly referencing the clinical and emotional challenges faced by healthcare professionals.[7] To augment our understanding of the challenges to providing effective multidisciplinary care, that meets the needs and expectations of patients and their informal support network, it is important to consider the experiences and perspectives of the professional care providers. Some studies have addressed the challenges of professional caregiving for specific groups of professionals such as doctors,[22] nurses[23,24] or primary care teams[25] and in specific circumstances such as supporting the withdrawal of non-invasive ventilation[26] or communicating the diagnosis.[14] However, this research has not been systematically reviewed to date.

This scoping review aims to identify healthcare professionals' experiences of working with this complex and progressive condition and determine what is currently known about the impact of working with motor neurone

Table 1. Selection criteria.

Population, concept and context	
Population	Healthcare professionals[a] – medical, nursing, allied health or any other professional providing care for motor neurone disease patients and/or their informal caregivers as part of the healthcare service
Concept	Healthcare professionals' perception of their experience of providing care or services for people living with motor neurone disease and/or their informal caregivers and/or their perception of the impact of providing care for people with motor neurone disease on their own emotional or psychological health or well-being
Context	Any healthcare setting such as, but not limited to, hospital, hospice, community, outpatient clinics, home care or residential care, that provide a public, private or voluntary healthcare service for people living with motor neurone disease and/or their informal caregivers
Types of studies	
Language	Studies published in the English language
Year	No limitation on timeframe
Study design	All original study designs including grey literature

[a]In this review the term 'professionals' will be used to define the population.

disease on the emotional and psychological well-being of all healthcare professionals involved. This review also aims to identify areas for important future research on this topic.

Design

This review is based on guidance from Arksey and O'Malley,[27] Levac et al.[28] and The Joanna Briggs Institute.[29] An *a priori* review Protocol is registered on Open Science Framework (https://osf.io/gkjme), and was followed throughout the review process.

Eligibility criteria

Development of the selection criteria (Table 1) was guided by the Population, Concept and Context (PCC) framework.[29] and determined the parameters of sources for inclusion.

Search strategy

Five electronic databases; Embase, Medline, Cinahl, PsychINFO and Web of Science were systematically searched in January 2023 and January 2024. The search strategy was developed with assistance from a medical librarian (DM), using keywords for 'motor neurone disease', 'multidisciplinary care', 'healthcare service', 'healthcare professionals' and 'experience' or 'perspectives'. See Supplemental Material for an example of one complete search strategy. All original study designs were included. Review articles were excluded but any relevant original studies within identified reviews were included. There was no limitation on year of publication, but sources were limited to the English language. In addition, grey literature was searched (*Open Grey, ProQuest Dissertations* and *Google Scholar*) using combinations of key words from database searching. MW completed a hand search in the reference list of each source selected for inclusion and in all review articles identified.

Data screening

All citations were exported to Covidence digital review management software,[30] for screening and data management. The lead reviewer (MW) screened all texts by title and abstract. Full texts were retrieved, read and reviewed by MW and cross-checked by the second reviewer (AC). Any disagreements were discussed, and when consensus could not be reached the third reviewer (MG) was consulted.

Data extraction

The data extraction tool was developed at the Protocol stage and pilot tested by the research team (Supplemental Material 2). The lead reviewer (MW) extracted; (1) study title, (2) author(s), (3) year of publication, (4) country of publication, (5) study design, (6) number of healthcare professional participants, (7) participants profession(s) (8) healthcare setting participants worked in, (9) experience of providing care as described by the professional and (10) any emotional or psychological response described or potential impact on their health or well-being.

Data analysis

As guided by Levac et al.[28] the characteristics of included sources were analysed using descriptive statistics in Microsoft Excel and qualitative data were analysed using conventional content analysis.[31] Qualitative data were imported to NVivo 12[32] for coding and categorisation, codes were derived directly from the data and sorted into categories and sub-categories to answer the review question. Methodological rigour of included sources was not assessed, as was not relevant to the aim of this review.[28] Findings are reported descriptively, in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews[33] (PRISMA-ScR; Supplemental Material 3).

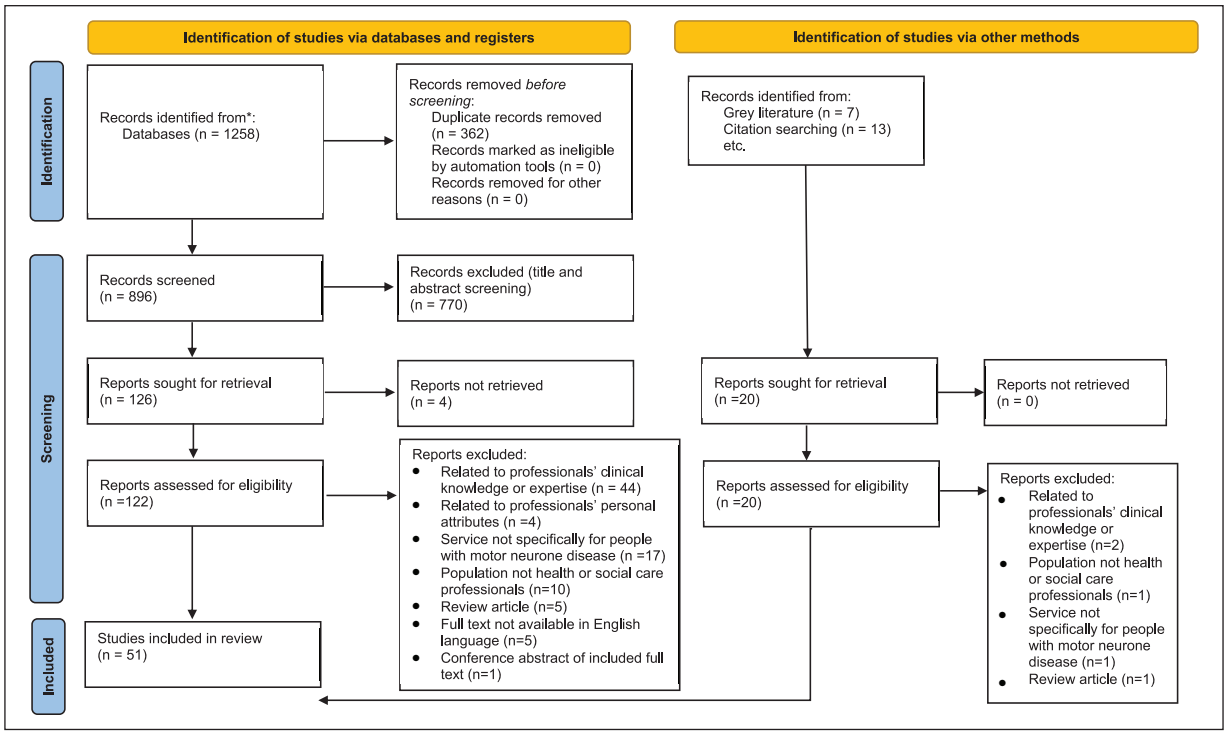

Figure 1. Preferred reporting items for systematic reviews and meta-analysis (PRISMA) diagram.[34]

Results

Results from the search strategy and selection process

The PRISMA diagram[34] (Figure 1) outlines the study selection process. A total of 1258 citations were identified from electronic databases (January 2023 and 2024). After duplicates were removed, 770 sources were excluded by title and abstract screening. 13 texts were identified from hand searching in the reference lists of included sources and 7 from the grey literature search. 142 full texts were reviewed and cross-checked, of these 51 met the inclusion criteria. Reasons for full text exclusion are reported in Figure 1.

Characteristics of included sources

Fifty-one sources were included in the review, of which $n = 42$ (82%) used qualitative, $n = 4$ (8%) quantitative and $n = 5$ (10%) a combination of both methods. European countries were most represented ($n = 31$), however there was wide global representation: USA ($n = 9$), Australia and New Zealand ($n = 8$), South America ($n = 2$), Canada ($n = 3$), Asia ($n = 2$) and South Africa ($n = 1$). Included sources were published between 1990 and 2023. An increase in interest on this topic was observed over time with $n = 16$ (31%) of all included sources published between 2021 and 2023. See all characteristics of included sources in Table 2.

Healthcare professionals represented

A total of 1692 professionals are represented from 15 different professional backgrounds (Figure 2). Medical $n = 558$ (33%) and nursing $n = 537$ (32%) professionals are more highly represented than allied health or social care professionals $n = 310$ (18%) combined. Profession or discipline was not reported for $n = 288$ (17%).

Healthcare settings

Professionals were working in six main healthcare settings. Hospice and palliative care were most highly represented ($n = 20$) followed by community/primary care ($n = 18$), hospital ($n = 17$) and specialist multidisciplinary team clinics ($n = 15$). Voluntary organisations ($n = 4$) and residential care facilities ($n = 2$) were least frequently represented. The majority of sources $n = 32$ (63%) recruited professionals from a single setting and only $n = 10$ (19%) recruited professionals from three or more different settings.

Results from the qualitative synthesis

Three main categories were generated: (1) The demands of providing motor neurone disease care (2) factors influencing professionals' ability to provide desired levels of care (3) The emotional impact of working with motor neurone disease. Sub-categories are depicted within each of these (Figure 3).

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Table 2. Characteristics and summary of data extracted from sources included in the scoping review.

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Chapman et al.[35]	2021	Communication Surrounding Initiation and Withdrawal of Non-Invasive Ventilation in Adults with Motor Neuron(e) Disease: Clinicians and family members perspectives	Australia	Interpretative descriptive qualitative design. Semi-structured interviews. Thematic analysis.	Healthcare professionals (*n* = 19) Nurse (*n* = 8) Medical (*n* = 9) Physiotherapist (*n* = 1) Social Worker (*n* = 1)	Specialist palliative care services, Hospital, Support (voluntary) organisation	– Engaging in difficult conversations/timing of communication – Time to deliver adequate care – Managing patient and family emotion – Patient and family psychological adjustment – Managing cognitive and behavioural changes – Multidisciplinary team communication and collaboration – Emotional impact of involvement with withdrawal of non-invasive ventilation
Aoun et al.[36]	2016	Breaking the News of a Diagnosis of Motor Neurone Disease: A National Survey of Neurologists Perspectives	Australia	Anonymous online survey.	Healthcare professionals (*n* = 69) Medical (*n* = 69)	Multidisciplinary Clinic Hospital	– Engaging in difficult conversations – Managing patient and family emotion – Time to deliver adequate care – Being honest without taking away hope – Clinician experience – Emotional impact of communicating a terminal diagnosis
Brown.[37]	2003	User, Carer and Professional Experiences of Care in Motor Neurone Disease	United Kingdom	Hermeneutic phenomenological qualitative design.	Healthcare professionals (*n* = 9) Speech and Language Therapist (*n* = 1) Nurse (*n* = 2) Dietitian (*n* = 1) Social Worker (*n* = 1) Medical (*n* = 2) Physiotherapist (*n* = 1) Occupational Therapist (*n* = 1)	Community Others not specified	– Intensity of care required – Individual approach – Support required by informal caregivers – Clinician experience – Clinician knowledge/ confidence – Ability to make a difference – Resource limitations – personnel, time, equipment, external economics – Multidisciplinary team communication and collaboration – Frustration – inability to achieve ideals of care – Emotional involvement – Taking on the '*burden of grief*'
Faull et al.[38]	2016	The Emotional Issues for Health Professionals Involved in the Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease	United Kingdom	Conference Abstract Qualitative interviews. Thematic Analysis	Healthcare professionals (*n* = 50) –Breakdown of participants professional background is not provided.	Not specified	– Above standard role – Legal, moral, ethical concerns – Emotional impact of involvement with withdrawal of non-invasive ventilation '*personal sadness*' – Long term emotional impact – Positive experience of fulfilling patient's wishes and ensuring a '*good death*'
McConigley et al.[39]	2014	Staying Just One Step Ahead: Providing Care for Patients with Motor Neurone Disease.	Australia	Descriptive, exploratory qualitative design. Interviews and focus groups. Thematic content analysis.	Healthcare professionals (*n* = 31) Nurse (*n* = 8) Occupational Therapist (*n* = 6) Case coordinator (*n* = 5) Medical (*n* = 3) Physiotherapist (*n* = 3) Speech Pathologist (*n* = 1) Complementary Therapist (*n* = 1) Counsellor (*n* = 1) Dietitian (*n* = 1) Prosthesis (*n* = 1) Chaplain(*n* = 1) –Some professionals listed more than one professional role.	Not specified	– Distinct from patients with other life limiting conditions – unique care needs – Individualised care – Importance of anticipatory care – Challenges responding to rapid disease progression – Patient and family psychological adjustment – Clinician experience – Clinician knowledge/confidence – Time to provide adequate care – Challenges with motor neurone disease associated communication impairment – Developing relationships with informal caregivers – Multidisciplinary team communication and collaboration – Engaging in difficult conversations

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Bromberg et al.[22]	2011	A Survey of Stress Among Amyotrophic Lateral Sclerosis Care Providers	USA	Quantitative online survey	Healthcare professionals (*n* = 63) Medical (*n* = 32) Clinic managers (*n* = 31; 23 clinic managers were nurses) 8 others (professional background not specified)	Multidisciplinary clinics	– Job satisfaction – Staff turnover/ intention to quit – Clinician experience – Organisational barriers – lack of personnel, time, finances – Emotional involvement – Clinician stress at each critical stage (diagnosis, managing care and death) influenced by patient characteristics, global circumstances, patient disease factors and acceptance of disease – Emotional impact of communicating a terminal diagnosis – Stress of working with amyotrophic lateral sclerosis not formally addressed
Gamskjaer et al.[40]	2021	Investigating Job Satisfaction in Palliative Rehabilitation: Reflections and Perspectives of Health Professionals Working with Amyotrophic Lateral Sclerosis	Denmark	Hermeneutic phenomenological qualitative design based on Paul Ricoeur's interpretation theory.	Healthcare professionals (*n* = 12) Nurse (*n* = 4) Psychologist (*n* = 2) Occupational Therapist(*n* = 1) Physiotherapist (*n* = 2) Social Worker (*n* = 2) Medical (*n* = 1)	Multidisciplinary Palliative Rehabilitation Team	– Job satisfaction – Ability to make a difference in the lives of others – Receiving gratitude – Clinician knowledge – Multidisciplinary team communication and collaboration – Gratitude for own health and personal life – Emotional involvement – Emotional exhaustion
Mitsumoto et al.[41]	2007	Palliative Care for Patients with Amyotrophic Lateral Sclerosis	USA	Case study with clinical reflection	Healthcare professionals (*n* = 1) Medical (*n* = 1)	Palliative care	– Multidisciplinary team communication and collaboration – Emotional involvement – vulnerability to stress and burnout – Experiencing '*extraordinary burdens and extraordinary opportunities providing expert care throughout this tragic illness*'
Lerum et al.[25]	2017	Healthcare Professionals Accounts of Challenges in Managing Motor Neurone Disease in Primary Healthcare: A Qualitative Study.	Norway	Qualitative Semi-structured interviews	Healthcare professionals (*n* = 18) Occupational Therapist (*n* = 3) Nurse (*n* = 11) Hospice Worker (*n* = 4; professional background not specified)	Community/ primary care Hospice	– Intensity of care required, prioritised over patients with other conditions – Importance of developing relationships with patients and families – Patient and family psychological adjustment – Support required by informal caregivers – Multidisciplinary team communication and collaboration – Clinician knowledge/skill – Clinician experience – Staff turnover and retention challenges
Carter et al.[42]	1998	Health Professionals Responses to Multiple Sclerosis and Motor Neurone Disease	New Zealand	Quantitative Questionnaire with open and closed questions	Healthcare professionals (*n* = 317) Nurse (*n* = 138) Physiotherapist (*n* = 59) General practitioners (*n* = 43) Occupational Therapists, Speech and Language Therapists, Social Workers and Dietitians (*n* = 77) breakdown not provided.	Hospital General practices Hospice	– Professionals felt less confident in their ability to manage the care of people with motor neurone disease than those with multiple sclerosis – Clinician knowledge and experience – Patient and family psychological adjustment – Managing the rate of disease progression – Ability to convey hope – Resource and service-related issues – difficulty accessing services, finances and medical devices – Multidisciplinary team communication and collaboration
Erlen et al.[43]	1990	Making an Ethical Decision in the Home Setting: The Case of Stan	USA	Case study	Healthcare professionals (*n* = 1) Nurse (*n* = 1)	Community	– Intensity of care required – Impacting ability to provide care for other patients – Overwhelmed by the multitude of clinical problems and when faced with making complex decisions about appropriate clinical care alone in the patients home – Moral and ethical concerns – autonomy vs beneficence – Support required by informal caregivers – Staff turnover and retention

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Carroll-Thomas[44]	1993	Ethics and the Clinician: The Daily Experience with Motor Neurone Disease	USA	Clinical reflection	Healthcare professionals (*n* = 1) Speech and Language Therapist (*n* = 1)	Not specified	– Importance of anticipatory care – Ethical concerns – patient choice vs beneficence – Balancing the needs of patients and informal caregivers – Managing expectations – Funding for assistive devices – Resource allocation
De Carvalho Costa et al.[45]	2020	Palliative Care to Patients with Amyotrophic Lateral Sclerosis: Experiences of Physiotherapists in a Hospital Setting	Brazil	Descriptive exploratory qualitative design. Semi-structured interviews. Content analysis.	Healthcare professionals (*n* = 8) Physiotherapist(*n* = 8)	Hospital	– Multidisciplinary team communication and collaboration – Clinician knowledge – Ability to make a difference – Emotional involvement – Lack of education about how to manage the emotional and moral suffering from this work
Hetzler.[46]	2021	Empowering People with ALS	USA	Clinical reflection	Healthcare professionals (*n* = 1) Physiotherapist (*n* = 1)	ALS and Huntington's Disease Multidisciplinary Team Clinic	– Patient and family psychological adjustment – Access to resources – Job satisfaction – Emotional involvement – Ability to make a difference and help people when they need it most – Receiving gratitude
Cornwell.[47]	2016	Clinical Issues for Working with Patients and Family Members Dealing with Amyotrophic Lateral Sclerosis	USA	Clinical Reflection	Healthcare professionals (*n* = 1) Psychotherapist (*n* = 1)	ALS clinic	– Managing patient and family emotion – Emotional involvement – Ability to make a difference – Perspective
Ruffell el al.[48]	2013	Healthcare Professionals Views on the Provision of Gastrostomy and Non-invasive Ventilation to Amyotrophic Lateral Sclerosis Patients in England, Wales and Northern Ireland.	United Kingdom	Online survey	Healthcare professionals (*n* = 177) Medical (*n* = 99) Nurse (*n* = 25) Physiotherapist (*n* = 9) Occupational Therapist (*n* = 3) Speech and Language Therapist (*n* = 11) Dietitian (*n* = 18) Care-coordinator (*n* = 7) Not Specified (*n* = 5)	Multidisciplinary clinics Hospital Palliative Care	– Individualised care – Timing of conversations – Clinician knowledge – Multidisciplinary team communication and collaboration
Martin et al.[49]	2016	Decision Making about Gastrostomy and Non-invasive Ventilation in Amyotrophic Lateral Sclerosis	United Kingdom	Qualitative Interviews Thematic analysis	Healthcare professionals (*n* = 19) Medical (*n* = 9) Nurse (*n* = 7) Dietitian (*n* = 1) Speech and Language Therapist (*n* = 1) Care Coordinator (*n* = 1)	Hospital Community Specialist MND clinics Hospice	– Individualised approach – Importance of anticipatory care – Engaging in difficult conversations/ timing of communication – Patient and family psychological adjustment – Influence of informal caregivers – Multidisciplinary team communication and collaboration – Clinician experience
Gale.[50]	2015	Assisting Patients with Motor Neurone Disease to Make Decisions About Their Care	United Kingdom	Case study	Healthcare professionals (*n* = 1) Nurse (*n* = 1)	Hospice	– Patient and family psychological adjustment – Individualised approach – Ethical issues – patient choice vs beneficence – Engaging in difficult conversations about advanced care planning

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Hogden et al.[51]	2012	Engaging in Patient Decision Making in Multidisciplinary Care for Amyotrophic Lateral Sclerosis: The Views of Health Professionals	Australia	Qualitative interviews Thematic analysis	Healthcare professionals (n = 32) Medical (n = 9) Nurse (n = 5) Physiotherapist (n = 4) Social Worker (n = 2) Occupational Therapist (n = 3) Speech and Language Therapist (n = 2) Dietitian (n = 2) Care Coordinator (n = 3) Research Staff (n = 1) Volunteer (n = 1)	Acute hospital Community rehabilitation Palliative care ALS clinics Motor Neurone Disease Association	– Individualised approach – Importance of anticipatory care – Managing family dynamics – Balancing the needs of patients and their families – Patient and family psychological adjustment – Managing cognitive and behavioural changes – Responding to rapid disease profession '*crisis situations*' – Clinician knowledge – Managing expectations – Time sensitive care – Timing of communication – Resources – funding, access to services – Multidisciplinary team communication and collaboration – Stress and frustration in relation to delays with decision making and acquiring resources to deliver care required by the patient at that time – Frustration with constraints imposed by factors outside of professionals control
Oliver et al.[52]	2010	Some Difficult Decisions in ALS/MND	United Kingdom	Clinical reflection with expert opinion	Healthcare professionals (n = 2) Medical (n = 2).	Hospice/ palliative care MND care centre	– Challenges with motor neurone disease associated communication impairments – Patient and family psychological adjustment – Balancing the needs of patients and informal caregivers – Multidisciplinary team communication and collaboration
Dengler et al.[53]	1997	Impact of Riluzole on the Relationship Between Patient and Physician	Germany	Clinical reflection with expert opinion	Healthcare professionals (n = 2) Medical (n = 2)	Not specified	– Difficulty communicating a terminal diagnosis – Managing patient and family emotion – Ability to convey hope and optimism – Individualised approach – Patients strong interest in ongoing research – Influence of informal caregivers on the patient-clinician relationship – Resources – delays with administration, finances and obtaining resources more problematic for this population – Difficulty coping with the inability to effectively intervene
Siewers et al.[54]	2013	Experiences with Using Mechanical In-exsufflation in Amyotrophic Lateral Sclerosis	Norway	Qualitative semi-structured interviews Thematic content analysis	Healthcare professionals (n = 3) Nurse (n = 3)	Community	– Clinician knowledge and skill – Intensity of care required – patients' dependence on professional caregivers – Clinician confidence with the use of aids and devices – Multidisciplinary team communication and collaboration – Time to provide appropriate care
Phelps et al.[55]	2017	Withdrawal of Ventilation at the Patients Request in MND: A Retrospective Exploration of the Ethical and Legal Issues that Have Arisen for Doctors in the UK.	United Kingdom	Retrospective thematic analysis of qualitative interviews	Healthcare professionals (n = 24) Medical (n = 24)	Hospital Community Residential Care Palliative Care	– Legal, moral and ethical dilemmas – withdrawing non-invasive ventilation at the end-of-life – Challenges of motor neurone disease associated communication impairments – Support required by informal caregivers – Multidisciplinary team communication and collaboration – Emotional involvement – Stress and fear about legality of withdrawing ventilation – Anxiety about perception of hastening death

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Faull et al.[26]	2014	Issues for Palliative Medicine Doctors Surrounding the Withdrawal of Non-invasive Ventilation at the Request of a Patient with Motor Neurone Disease: A Scoping Study.	United Kingdom Ireland	Mixed categorical and free text online questionnaire. Descriptive statistics and thematic analysis using constant comparison based on grounded theory	Healthcare professionals (*n* = 130) Medical (*n* = 130)	Not specified	– Moral and ethical uncertainty – withdrawing non-invasive ventiliation – Identified as more stressful than most other areas of practice – Intensity of care – Patient and family psychological adjustment – Managing the emotion of others – Support required by informal caregivers – Multidisciplinary team communication and collaboration – Difficulty ensuring autonomy with motor neurone disease associated communication impairments and/or cognitive and behavioural changes – Emotional involvement – stress, anxiety, emotional drain
Phelps et al.[56]	2022	Withdrawal of Assisted Ventilation at the Patients Request in MND/ALS: A Retrospective Exploration of the Ethical and Legal Issues Concerning Relatives, Nurses and Allied Health Care Professionals.	United Kingdom	Retrospective analysis of qualitative interviews Constant comparison analysis based on grounded theory	Healthcare professionals (*n* = 25) Nurse (*n* = 19) Physiologist (*n* = 2) Physiotherapist (*n* = 2) Social Worker (*n* = 1) MND care coordinator (*n* = 1)	Community Palliative Care Motor Neurone Disease Association	– Legal, moral and ethical uncertainty – withdrawal of non-invasive ventilation – '*Ethical burden and emotional stress*' – Intensity of care – time burden – Above '*usual practice*' – Clinician knowledge and experience – Multidisciplinary team communication and collaboration – Support required by informal caregivers – Fear of ethical and legal repercussions – Rewarding experience – helping patients and families through difficult decisions and processes – Emotional involvement – profound lasting effects due to emotional intensity of events surrounding the withdrawal – Fear and anxiety about perception of hastening death
Baxter et al.[57]	2013	The Use of Non-invasive Ventilation at End of Life in Patients with Motor Neurone Disease: A Qualitative Exploration of Family Carer and Health Professional Experiences	United Kingdom	Longitudinal qualitative study Thematic analysis	Healthcare professionals (*n* = 15) Physiotherapist (*n* = 2) Occupational Therapist (*n* = 3) Nurse (*n* = 8) Medical (*n* = 2)	Community/ Primary care Palliative care Neurology support team	– Managing rapid disease progression – Timing of communication – Patient and family psychological adjustment – Support required by informal caregivers – Clinician knowledge – Positive experience of providing comfort and reassurance for the patient/ family
LeBon et al.[58]	2010	Case Report: Maintaining and Withdrawing Long-term Invasive Ventilation in a Patient with MND/ALS in a Home Setting	United Kingdom	Case Report	Healthcare professionals (*n* = 2) Medical (*n* = 2)	Specialist palliative care	– Legal, moral and ethical uncertainty – withdrawing treatment at a patient's request – Intensity of care '*exceptional team effort*' – Engaging in difficult conversations – Patient and family psychological adjustment – Multidisciplinary team communication and collaboration – Emotional involvement – emotional support required by professional care team
Oliver[59]	2004	Ventilation in Motor Neurone Disease: Difficult Decisions in Difficult Circumstances	United Kingdom	Case study with clinical reflection	Healthcare professionals (*n* = 1) Medical (*n* = 1)	Hospice/ palliative care	– Engaging in difficult conversations – Ethical dilemmas – balancing the needs of patients and family caregivers Challenges with motor neurone disease associated communication impairments – Patient and family psychological adjustment – Multidisciplinary team communication and collaboration
Olesen et al.[60]	2022	Reflections of Family Caregivers and Health Professionals on the Everyday Challenges of Caring for Persons with Amyotrophic Lateral Sclerosis and Cognitive Impairments a Qualitative Study	Denmark	Qualitative focus group and semi-structured individual interviews. Interpretative description analysis guided by theory of sense of coherence	Healthcare professionals (*n* = 8) Nurse (*n* = 3), Occupational Therapist (*n* = 2), Social care assistants (*n* = 3)	Community	– Intensity of care – constant progression – Managing cognitive and behavioural changes – Support required by informal caregivers – Time to provide adequate care – Clinician knowledge – Managing expectations – Clinician experience – Multidisciplinary team communication and collaboration – Emotional involvement – emotional distancing

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Ushikubo et al.[61]	2021	Practical Measures for Dealing with the Struggles of Nurses Caring for People with Amyotrophic Lateral Sclerosis Comorbid with Cognitive Impairment in Japan	Japan	Cross-sectional qualitative descriptive design with a questionnaire survey and focus group interviews	Healthcare professionals (*n* = 139) Nurse (*n* = 137) Social Worker (*n* = 1) Medical (*n* = 1)	Community/ public health centres Hospital	– Intensity of care – time burden – nurse exhaustion – Ethical dilemmas – patient autonomy vs beneficence – Patient and family psychological adjustment – Managing cognitive and behavioural changes – Challenges ensuring autonomy with motor neurone disease associated communication impairments – Support required by informal caregivers – Multidisciplinary team communication and collaboration
Crockford et al.[62]	2017	Clinicians Attitudes Towards Cognitive and Behavioural Screening in Motor Neurone Disease	Scotland United Kingdom	Structured qualitative interviews consisting of both open ended and forced choice questions Thematic analysis	Healthcare professionals (*n* = 14) Medical (*n* = 5) Psychologist (*n* = 4) ALS clinical care specialists (*n* = 5) – Profession not specified	NHS health boards	– Managing cognitive and behavioural changes – Multidisciplinary team communication and collaboration – Patient and family psychological adjustment – Clinician knowledge – Lack of resources – time, staffing levels, access to training and appropriate assessment tools – Geographical variation in services available
Gray et al.[63]	2022	International Evaluation of Current Practices in Cognitive Assessment for Motor Neurone Disease	Africa (South Africa) Asia (China) Australia/New Zealand Europe (Austria, Belgium, Bosnia Herzegovina, Croatia, Denmark, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden). North America (Canada) South America (Peru, Colombia)	Online survey consisting of quantitative closed responses and open-ended text responses Descriptive statistics and framework analysis methods	Healthcare professionals (*n* = 80) Medical (*n* = 47) Nurse (*n* = 4) Psychologist (*n* = 7) Clinical care coordinator (*n* = 6) Allied health professional (*n* = 7) – Breakdown of AHPs not provided Other/not disclosed (*n* = 10)	Specialist MND/ ALS clinics	– Managing cognitive and behavioural changes – Time to provide adequate care – Clinician knowledge – Patient and family psychological adjustment – Resources – staffing
O'Brien et al.[64]	2022	Palliation in a Pandemic: The Human Cost of Achieving the Greater Good	Ireland	Case study	Healthcare professionals (*n* = 1) Medical (*n* = 1)	Hospice/ Palliative care	– Motor neurone disease patient viewed by palliative care staff as an '*exceptional case*' – Challenges delivering motor neurone disease care during COVID 19 – Ethical dilemmas – visiting policies and end-of-life care – Challenges associated with motor neurone disease associated communication impairment – Emotional involvement
Coates et al.[65]	2021	Patient, Carer and Healthcare Professional Perspectives on Increasing Calorie Intake in Amyotrophic Lateral Sclerosis	United Kingdom	Multi-center qualitative design Focus group interviews with template data analysis approach.	Healthcare professionals (*n* = 51) Medical (*n* = 8) Nurse (*n* = 10) Dietitian (*n* = 15) Speech and Language Therapist (*n* = 6) Occupational Therapist (*n* = 3) Physiotherapist (*n* = 2) Community Outreach (*n* = 1) Psychologist (*n* = 1) Care Coordinator (*n* = 5)	Multidisciplinary clinics	– Importance of anticipatory care – Managing rapid disease progression – Individualised approach – Time to provide adequate care – Resources – staffing, funding, inconsistent team composition – Geographical variation in services available – Clinician knowledge and experience – Patient and family psychological adjustment – Cognitive and behavioural changes – Support provided by informal caregivers

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Zarotti et al.[66]	2019	Healthcare Professionals Views on Psychological Factors Affecting Nutritional Behaviour in People with Motor Neurone Disease: A Thematic Analysis.	United Kingdom	Qualitative focus group interviews Thematic analysis	Healthcare professionals (*n* = 47) Dietitian (*n* = 25) Medical (*n* = 2) Clinic coordinator (*n* = 2) Nurse (*n* = 11) Physiotherapist (*n* = 1) Speech and Language Therapist (*n* = 6)	Community Hospital	– Managing disease progression – Clinician knowledge – Individual approach – Patient and family psychological adjustment
James et al.[67]	2018	Healthcare Professionals Perspectives of Multidisciplinary Home-based E-health for Amyotrophic Lateral Sclerosis	Australia	Conference abstract Qualitative focus group interviews Stepwise inductive approach to data analysis	Healthcare professionals (*n* = 15) – Professional backgrounds not reported	Specialist ALS clinics	– Individualised approach – Resource limitations – Importance of relationship building
Andrews et al.[68]	2020	Amyotrophic Lateral Sclerosis Care and Research in the United States During the COVID-19 Pandemic: Challenges and Opportunities	USA	Quantitative online survey Descriptive statistics	Healthcare professionals (*n* = 61) – Professional backgrounds not reported Surveys disseminated to members of the Northeast ALS (NEALS) Consortium	ALS clinics	– Challenges delivering care during COVID 19 – inability to deliver optimal care
Musson et al.[69]	2022	Impact of the COVID-19 Pandemic on Amyotrophic Lateral Sclerosis Care in the UK.	United Kingdom	Cross-sectional online survey Combination of closed ended and open ended questions Descriptive and inferential statistics and thematic analysis	Healthcare professionals (*n* = 73) Nurse (*n* = 22), Medical (*n* = 18), Not specified (*n* = 33)	Not specified	– Challenges delivering care during COVID 19 – concerns about inability to deliver optimal care and the implications of this on patients' quality of life and survival – Multidisciplinary team working and collaboration – Psychological impact on staff well-being
Rolland et al.[70]	2021	The Assistive Device Situation for ALS Patients in Norway	Norway	Qualitative semi-structured interviews Systematic text-condensation analysis	Healthcare professionals (*n* = 7) Occupational Therapist (*n* = 6) Physiotherapist (*n* = 1)	Community/ primary healthcare Specialist ALS service	– Importance of anticipatory care – Patient and family psychological adjustment – Geographical variation in services – Bureaucratic processes
Casey et al.[71]	2011	Creating an Assistive Technology Clinic: The Experience of the John Hopkins AT Clinic for Patients with ALS	USA	Qualitative case presentation and clinical reflection	Healthcare professionals (*n* = 1) Occupational Therapist (*n* = 1)	ALS specialist clinic	– Clinician knowledge – Clinician confidence with assistive devices and technology – Resources – funding for assistive devices, availability of devices – Patent and family psychological adjustment – Multidisciplinary team communication and collaboration
Bakker et al.[72]	2015	Need and Value of Case Management in Multidisciplinary ALS Care: A Qualitative Study on the Perspectives of Patients, Spousal Caregivers and Professionals	The Netherlands	Qualitative semi-structured interviews and focus group Inductive content analysis	Healthcare professionals (*n* = 20) Medical (*n* = 9) Case managers (*n* = 2) Speech and Language Therapist (*n* = 1) Psychologist (*n* = 2) Physiotherapist (*n* = 2) Occupational Therapist (*n* = 2) Social Worker (*n* = 2)	Not specified	– Managing rate of disease progression – Multidisciplinary team communication and collaboration – Patient and family psychological adjustment – Support provided by informal caregivers – Time to provide adequate care

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Cutler[23]	2009	The Experiences of Hospice Nurses who Care for People with Motor Neurone Disease.	United Kingdom	Conference abstract Qualitative semi-structured interviews with interpretative phenomenological analysis	Healthcare professionals (*n* = 6) Nursing (*n* = 6)	Hospice	– Managing disease progression – Challenges of motor neurone disease associated communication impairments – Clinician knowledge and experience – Multidisciplinary team communication and collaboration – Experience of caring for patients with motor neurone disease identified as both '*challenging and very satisfying*'
Brewah.[73]	2019	A Qualitative Study of the Preparedness of Practitioners to Care for People with Motor Neurone Disease in their Homes	United Kingdom	Qualitative	Not specified	Not specified	– Managing disease progression – Anticipatory care – Challenges with motor neurone disease associated communication impairments – Multidisciplinary team communication and collaboration – Clinician knowledge and experience – Emotional involvement – emotional challenges and relationship building
Ushikubo et al.[74]	2012	Circumstances Surrounding Death and Nursing Difficulties with End-of-Life Care for Individuals with ALS in Central Japan	Japan	Questionnaire Descriptive design collecting brief quantitative data and qualitative responses to an open-ended question Descriptive analysis and inductive content analysis.	Healthcare professionals (*n* = 39) Nursing (*n* = 39)	Home care nursing	– Managing disease progression – Time to provide adequate care – Patient and family psychological adjustment – Support required by informal caregivers – Challenges with motor neurone disease associated communication impairments – Ethical dilemmas – Balancing the needs of patients and informal caregivers, patient autonomy vs beneficence – Multidisciplinary team communication and collaboration
Alquati et al.[75]	2022	Negotiating the Beginning of Care: A Grounded Theory Study of Health Services for Amyotrophic Lateral Sclerosis	Italy	Constructivist grounded theory method Semi-structured interviews employing theoretical sampling and constant comparison Conceptual coding data analysis	Healthcare professionals (*n* = 12) Physical Therapist (*n* = 1) Speech Therapist (*n* = 1) Dietitian (*n* = 1) Medical (*n* = 5) Not Specified (*n* = 4)	Hospital palliative care unit	– Importance of anticipatory care – Individualised approach – Patient and family psychological adjustment – Engaging in difficult conversations
Hughes et al.[13]	2004	Living with Motor Neurone Disease: Lives, Experiences of Services and Suggestions for Change	United Kingdom	Exploratory and descriptive qualitative design Semi-structured interviews	Healthcare professionals (*n* = 15) Nurses, other clinicians and managers, breakdown not reported.	Hospital Community Social care service	– Prioritised over other conditions – Patient and family psychological adjustment – Multidisciplinary team communication and collaboration
Cipolletta et al.[76]	2021	End-of-Life Care After the Legal Introduction of Advance Directives: A Qualitative Study Involving Healthcare Professionals and Family Caregivers of Patients with Amyotrophic Lateral Sclerosis	Italy	Qualitative focus groups with thematic analysis	Healthcare professionals (*n* = 24) Physicians (*n* = 12) Nurses (*n* = 7) Psychologists (*n* = 5)	Community/ primary care Hospital Amyotrophic Lateral Sclerosis Association	– Managing disease progression – Patient and family psychological adjustment – Engaging in difficult conversations – Timing of conversations – Time to provide adequate care – Multidisciplinary team communication and collaboration – Balancing the needs of patients and informal caregivers – Emotional involvement – lack of preparation to deal with the emotive aspects of the communication process

(Continued)

Table 1. (Continued)

Author	Year	Title	Country	Study design and methods.	Number of health care professional participants	Healthcare settings	Data extracted as relevant to scoping review
Hennessey[77]	2016	Neurologists Emotional Experiences in Caring for Individuals with Amyotrophic Lateral Sclerosis: An Exploratory Study	USA	Qualitative Semi-structured interviews Grounded theory analysis influenced by Glaser and Strauss (1967)	Healthcare professionals (n = 11) Medical (n = 11)	ALS clinics	– Emotional difficulty communicating a terminal diagnosis – Frustration – lack of a cure – Timing of communication – Managing patient and family emotion – Support for informal caregivers – Balancing the needs of patients and informal caregivers – Clinician experience – Multidisciplinary team communication and collaboration – Organisational barriers – lack of time, services, financial obstacles – Managing cognitive and behavioural changes – Job satisfaction – rewarding experience – Ability to make a difference – Receiving gratitude – Perspective – Emotional involvement – emotional exhaustion, burden, burnout – Coping strategies – compartmentalising
Daneau et al.[24]	2023	Intensive palliative care': a qualitative study of issues related to nurses' care of people with amyotrophic lateral sclerosis at end-of-life	Canada	Qualitative semi-structured interviews content analysis method of Miles et al. (2020)	Healthcare professionals (n = 24) Nurse (n = 24)	Hospital Hospice/ Palliative Care Home Care	– Intensity of care – impacting ability to care for other patients – Time to provide adequate care – Challenges with motor neurone disease associated communication impairments – Patient and family psychological adjustment – Clinician experience – Manging cognitive and behavioural changes – Balancing the needs of patients and informal caregivers – Engaging in difficult conversations – Multidisciplinary team communication and collaboration – Staff retention – 'exhausted care team' – Rewarding nature of the work – Emotional involvement – feelings of helplessness
Beyermann et al.[78]	2023	Nurses' challenges when supporting the family of patients with ALS in specialised palliative home care: A qualitative study	Sweden	Qualitative explorative design Interviews qualitative content analysis according to Graneheim and Lundman (2017)	Healthcare professionals (n = 11) Nurse (n = 11)	Specialised Palliative Home Care	– Individualised approach – Collaboration with informal caregivers – Balancing the needs of patients and informal caregivers – Multidisciplinary team communication and collaboration – Receiving gratitude – Emotional involvement
Kloos[79]	2023	Defining Moment: Searching for Answers	USA	Clinical reflection	Healthcare professionals (n = 1) Physiotherapist (n = 1)	ALS centre of excellence	– Multidisciplinary team communication and collaboration – Ability to make a difference – Job satisfaction – personal and professional fulfilment

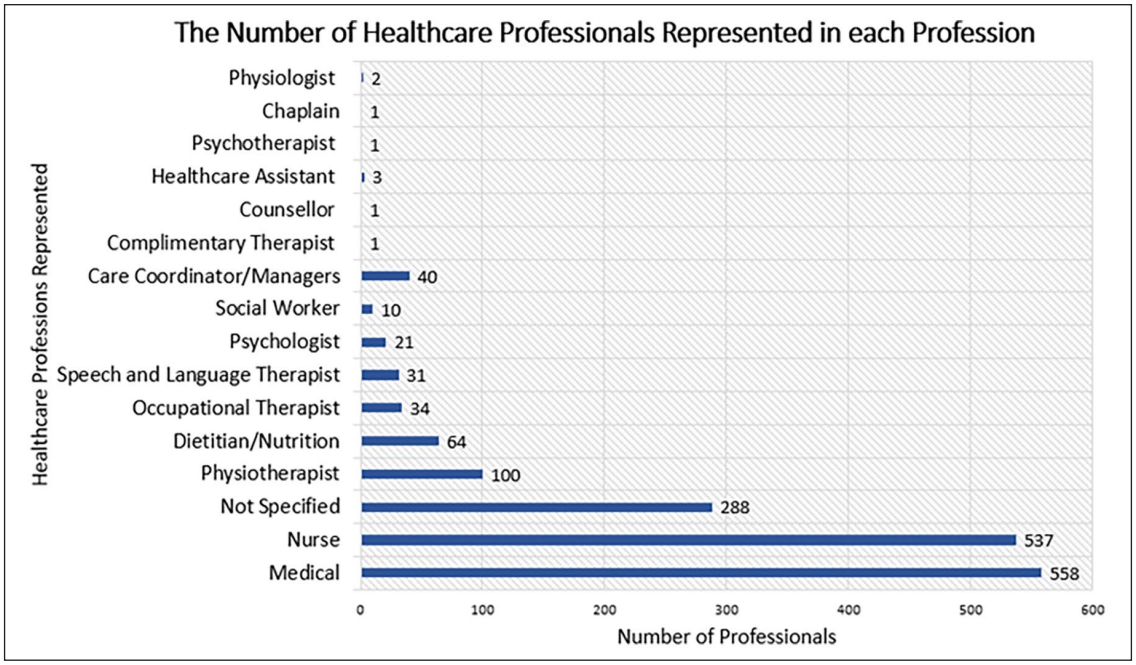

Figure 2. The number of healthcare professionals within each of the represented professions.

The demands of providing motor neurone disease care

Intensive, time-sensitive and individualised care. Providing care for people living with motor neurone disease and their families required exceptional multidisciplinary team effort.[23,25,58,64] Professionals described going above their '*usual practice*' or '*typical role*' to meet the complexity and extent of patient care needs.[13,23,37,38,44,55,56] Their care was described as distinctive and often prioritised over patients with other conditions.[13,24,25,39] Some professionals were described as committed and passionate,[61,65,77] while others avoided working with this population due to the perceived complexity.[25] Nurses particularly described the intensity of care as physically and mentally exhausting and the associated workload as limiting their capacity to care for other patients.[43,61,78] In one source the unequal time nurses had to give to those with motor neurone disease, over others in their care, caused them '*ethical discomfort*' and they felt that reduced patient-to-nurse ratios were required to provide safe and quality care for these patients.[78]

The continuous, heterogeneous, unpredictable and often rapid nature of disease progression is a unique feature of motor neurone disease, that contributed to professionals feeling under '*time pressure*' and '*working within windows of opportunity*'.[13,24,35,37,39,51,57,60,65,66,72–74] Professionals in many sources reported having inadequate time to address all the clinical needs motor neurone disease patients presented with.[14,22,24,26,35,37,39,43,49,54–56,58,60–62,65,76] Professionals could feel overwhelmed by the multitude of clinical problems[40,43] and perceived the duration of standard appointments as insufficient to adequately address all identified issues.[62,65] Homecare nurses in one source felt able to provide adequate person-centred care, because of additional time available to them.[72]

Interventions and care needed to be individualised for each patient and family.[35,37,39,49,56,67,75,77] Developing relationships with patients and families was important to understand their needs and priorities and facilitate an individualised approach to their care.[23,25,37,65,78] Professionals expressed concerns about quality of care in the absence of a patient-provider relationship.[25] However, they acknowledged that developing and sustaining relationships with these patients and families required emotional effort and adjusting their demeanour and approach for each individual situation was challenging.[37]

The need for specialist knowledge, skills and experience. Having up to date knowledge about the condition and available treatments was essential[37,39,42,60,66] as patients hope for a cure, meant they often sought information from multiple sources[51] and were interested in ongoing research.[53] Keeping up to date with evidence and the availability of services was difficult for professionals who provided this care infrequently.[37,39,66] One General Practitioner stated:

> *the clients with MND usually know about them [treatments] before us. . . you know they're on the internet*.[39]

Professionals who specialised in motor neurone disease care valued having specific and profound knowledge,[40]

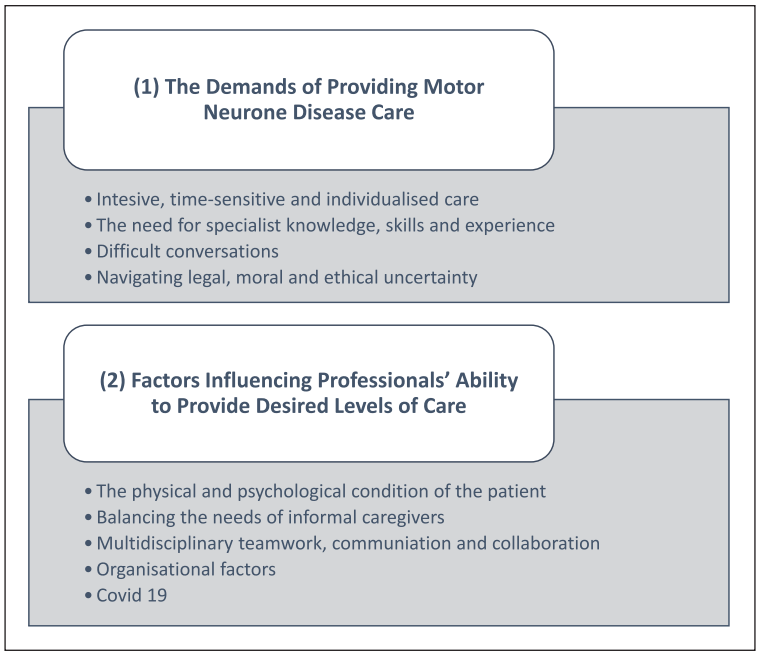

Figure 3. Overview of categories one and two and the sub-categories within each main category.

while access to expert knowledge was important to those who encountered the condition less frequently.[24,60]

In many sources, professionals acknowledged their limitations in having the required skills and experience to confidently provide motor neurone disease care.[37,39,45,56,60,62,66] Nurses reported needing to draw on all their nursing skills to meet the associated challenges.[39,46] In one source, professionals felt significantly less confident managing patients with motor neurone disease than those with a less progressive neurological condition.[42] Lack of confidence with the use of medical equipment, assistive devices and technology commonly used by these patients was also discussed.[25,54,60]

Some felt that previous experience allowed them to provide greater hope and optimism for motor neurone disease patients and their families. They felt able to talk about what could be done to manage symptoms and offer solutions rather than just seeing barriers.[42,60] More years of experience was related to lower levels of stress for doctors and clinic managers in one source,[22] while neurologists who were not experiencing burnout were working with motor neurone disease for longer than those experiencing burnout in another.[77] Many professionals felt that most of what they learned about providing motor neurone disease care was through their prior clinical experiences[37,56,65,77]; others felt that previous experience did not necessarily help with the most challenging aspects, such as end-of-life care conversations.[35]

Difficult conversations. In one source 65% of neurologists reported 'moderate-high' levels of stress and anxiety on delivering the diagnosis and 43% reported finding it 'very – somewhat' difficult responding to patients' emotional reaction to the diagnosis.[36] Neurologists in another source reported this to be the most emotionally challenging aspect of their job and that delivering more than three diagnoses in a day, could leave them emotionally and physically exhausted.[77] 73% struggled to reveal the diagnosis to a patient they personally identified with because of a demographic similarity such as age, gender, family composition or career; one neurologist reported '*having a migraine after each MND clinic and feeling stressed and anxious about having so little to offer*'.[36] In multiple sources, professionals struggled because of the lack of a cure for this disease.[36,42,53,60,77]

Eight sources discussed the dilemma professionals faced when determining the appropriate time to introduce conversations about advanced care planning, palliative or end-of-life care.[26,35,44,48,49,51,57,76] Professionals aimed to start these conversations early, recognising that skilled communication and good clinical judgement was required to determine the appropriate time for each individual.[38,44,49,51,57,76,80] This involved considering factors such as the rate of disease progression, social factors, coping and acceptance and challenged even those experienced in delivering motor neurone disease care.[49] Professionals found it difficult to provide honest information without taking away the person's sense of hope or optimism.[14,42,51,77] They feared causing additional distress and wanted to avoid '*piling on the bad news*'.[24,63]

Conversations about end-of-life could be uncomfortable, overwhelming and, sometimes avoided by professionals,[24,26,52] with some families wanting to discuss issues such as euthanasia and physician assisted suicide.[55]

Professionals experienced anxiety about engaging patients in conversations about advance care planning when they were still relatively well.[50] Being comfortable talking about end-of-life[39] and having a positive perspective on working with death was considered helpful, but difficult, for most.[40] Professionals perceived that a big part of their job was often '*to be present without intervening*'[40], '*to be a listener*[37]', '*simply allowing them to be sad*'[40] or '*taking on the burden of grief*'.[24,37,77] Those working in specific palliative care positions were more comfortable with difficult conversations about signs of deteriorating health, than those without palliative care experience.[24,42,58]

Navigating legal, moral and ethical uncertainty. Legal, moral and ethical dilemmas were frequently described in relation to decision making, planning, communicating and managing end-of-life care.[24,26,50,55,56,58,64,74,76] The withdrawal of non-invasive ventilation raised significant legal, moral and ethical concerns for professionals involved in this process.[26,55,56,58] The legal and ethical complexity was compounded when the underlying reason for the patient requesting ventilation withdrawal was their wish to die, rather than the removal of burdensome treatment.[55,56] Several sources also discussed the ethical dilemma professionals faced between respecting patient autonomy and beneficence.[43,44,59,60,64,74] Circumstances were described when professionals were faced with complex ethical dilemmas between supporting patient wishes and ensuring their own, the patients or informal caregivers' safety or welfare.[43,60,74]

Factors influencing professionals' ability to provide desired levels of care

The physical and psychological condition of the patient. The rate of disease progression could impact the quality of care provided.[26,57,65,72,74] Professionals described situations when the patient's condition changed more rapidly or abruptly than expected, rendering current supportive measures immediately ineffective.[57,66] Professionals were required to respond rapidly to what were described as '*crisis*' situations.[39,51] With a slower rate of progression, the need for assistive devices, home care services and other supports were less acute and professionals had time to effectively plan and support implementation.[72] Professionals highlighted the need to take a proactive or anticipatory approach to deliver good care for these patients.[39,44,48,49,51,65,70,75] They aimed to stay '*one step ahead*' by anticipating, planning and preparing for interventions before they were required[39,44,49,51] and described how situations could spiral into '*chaos*' when professionals were unprepared or uncertain about the trajectory of deterioration.[25,35,39]

Patient psychological adjustment and coping was discussed in 13 sources.[13,24,25,35,42,46,49–51,65,66,72,76] Acceptance[13,49,51,65,75] and denial[24,25,35,49,51,66] were raised as enablers and barriers to the level of care that could be provided. How patients adjusted to the diagnosis or deterioration in their condition influenced when interventions were provided. Patient and family acceptance of the diagnosis could influence clinician's stress levels.[44] Patients with some degree of acceptance of their condition, were perceived as more open to discussions, engaged in decision making and pro-active in managing their symptoms.[49,66]

The '*need for control*' could vary between patients, for some it manifested as taking control of managing their condition while for others it was exerted as avoidance or disengagement.[66] Professionals encountered patients who were in denial or shock at the terminal nature of the diagnosis and avoided engaging with services. This was frustrating, as it significantly limited their ability to deliver what was perceived as good anticipatory care.[51,62,76]

Professionals found it challenging to manage cognitive and behavioural symptoms motor neurone disease patients presented with.[62,77] Cognitive and behavioural changes impacted patients' understanding of information and the quality and timing of their healthcare decision making.[35,51,61,63,65,77] It also impacted their ability to use aids and devices such as high-tech communication aids and powered wheelchairs.[61,63] Professionals felt that patients who received cognitive and behavioural screening, received better clinical care, as their difficulties were identified and validated;[51,63] without routine cognitive screening, mild cognitive changes were not always identified.[51] Professionals felt that more specific and detailed knowledge of these symptoms could improve their approach with these patients.[51]

Presence of communication impairments presented particular challenges.[23,24,39,42,73] Professionals highlighted that having knowledge of communication devices and how to effectively use them was essential to provide good care[39,73] and that training for professionals on how to use these devices should be addressed.[73] Understanding patient's wishes, ensuring they were appropriately included in discussions and respecting their autonomy was challenging when communication was a problem.[24,26,55,73,74]

Balancing the needs of informal caregivers. Professionals recognised the important role of informal carers and the exhausting level of care they provided.[37,39,74,78] '*The heavy care burden brought the family to the verge of ruin*'.[74] Professionals reported difficulty assessing how much strain the family could manage[25] and providing emotional support and hope, in the face of deteriorating illness.[60,78] They were exposed to '*a lot of tears, frustrations and helplessness*'[60] and found it '*awful to look at*'[25] the emotional distress and burden family members experienced.[78] Some felt pressured for time or lacked knowledge about how best to support families.[60,78]

It was important for professionals to develop good relationships with family caregivers as in many cases they were the conduit between the patient and the care

team.[24,39,78] Professionals described collaboration with families as a balancing act and often encountered dilemmas and family dynamics.[24,49,51,52,60,74,77,78] Lack of concordance between the wishes of the patient and their family made things more difficult for the team supporting them.[49] Decision making was challenging when the patient and their family could not reach agreement, patient's decision-making placed family members at risk,[51,78] or family members engaged in activities that were deemed unsafe for the patient.[81] Professionals were required to take both sides into account:

> *I don't think you can only talk to the person with ALS and find out just what they want, because what their carer wants might be totally different. . . The client might say I want to stay at home, it's the only thing I want to do', and the partner might be going 'there is no way I can handle physically their behaviours'. So, you've got to take both into consideration*[51]

Multidisciplinary teamwork, communication and collaboration. Managing the complex needs of motor neurone disease patients and their families, required a large team and a union of authorities, teams and professionals.[39,60] Co-ordinating the number of people involved was a frequently cited challenge.[39,51,60,74,76] There could be uncertainty about who's role it was to co-ordinate patient care or the clinician responsible for initiating certain discussions or interventions.[26,35,62,76] Professionals counteracting or duplicating each other's work was experienced when '*one side doesn't know what the other is doing*'.[39] Feelings of frustration and powerlessness were experienced by professionals working with external teams who did not assign the same level of priority to motor neurone disease care,[40] or refused to provide a service, due to the perceived level of complexity.[25,40,60] The need for better communication and transfer of information between the teams and services involved was identified.[13,35,39,76]

The value of multidisciplinary team working, and strong professional relationships was discussed in 21 sources.[23,24,26,37,40–42,51,52,55,56,58–60,69,72,73,76–79] Six sources described challenges when there were differences of opinion about how care be provided within the healthcare team.[26,52,55,56,62,74] Effective teamworking was important for professionals and contributed to their job satisfaction.[40,79] When professionals worked in what they perceived as a well-functioning multidisciplinary team, they felt enabled to deliver effective support and care for patients and their families.[52,60,69] Professionals also recognised the emotional support they received from working within a strong multidisciplinary model of care.[23,40,41,52,55,59,77,78] Professionals reported that collegial support was invaluable in helping them to process '*heavy*' thoughts and emotions that arose from the difficult situations they were faced with when working with these patients.[40] In the absence of team support professionals reported feeling overwhelmed,[43] vulnerable[56] and isolated[25] when faced with making decisions or providing care alone. This was particularly relevant for nurses and healthcare assistants providing care in patient's homes.[25,43,78]

Organisational factors. Ten sources referenced lack of personnel or high rates of staff turnover as a problem for delivering consistent and high-quality care.[22,24,25,37,43,62,63,65,67,77] 29% of neurologists and 34% of motor neurone disease clinic managers in one source considered leaving their position due to stress or financial issues.[22] High rates of turnover resulted in inconsistent team composition and prevented important aspects of care from being delivered,[25,43,62,63,65,67] for example, lack of neuropsychologists prevented routine cognitive assessment in multidisciplinary clinics.[63]

It could be challenging to recruit professionals to work with motor neurone disease patients, as '*people avoided*' working with this patient group. High levels of turnover made it challenging to develop professionals' expertise and retain professionals with the required level of competency to meet the demands of motor neurone disease patient care.[25] With low staff turnover, professionals established a connection with their patients that allowed them to gather sensitive and personal information about their care preferences. This was considered essential to provide good person-centred care.[25]

Availability of finances, resources, access to services and assistive devices were identified as barriers by professionals in 14 sources.[22,25,37,42,43,46,53,58,62,65,67,70,71,77] Geographical variation in funding and services available impacted equitable service delivery.[62,65,70] Professionals identified that standard pathways for accessing services and medical devices were inappropriate for these patients.[51,53] Long delays with administration and obtaining financial approval was more problematic for this population than other less quickly progressing diseases.[53] A number of sources discussed how bureaucratic processes resulted in patients receiving necessary medical aids or devices after the disease had further progressed and the device was no longer suitable.[25,37,46,51,53,70,71,51] Professionals found this stressful,[51] while organisational factors such as being understaffed and institutional demands contributed to others experiencing burnout.[77]

Covid 19. Healthcare professionals' experiences of delivering motor neurone disease care for patients during the COVID-19 pandemic was discussed in three sources from 2020 to 2022.[64,68,69] Enforcing visiting restrictions was described as causing '*palpable distress*' and '*emotional devastation*' for members of a palliative care team involved in the care of a young lady with motor neurone disease. This case was identified as an '*exceptional case*' and '*ethically challenging*' for the staff involved, due to the patient's motor neurone disease associated communication impairment. She could not use technology to

engage with her family, as others could and staff viewed the restrictions imposed as '*wrong on so many levels*'.[64]

Specialists' ability to carry out important assessments, such as the physical examination required to confirm the diagnosis and spirometry testing, one of the key assessments for monitoring disease progression could not be completed virtually.[68] Professionals reported feeling concerned about missing important clinical details and the impact of this on the patient's quality-of-life and survival.[69] Professionals also experienced delayed access to key services including gastrostomy insertion, provision of wheelchairs and home help and hospice services being unavailable at certain times.[68] Professionals described how they developed new models of service delivery to overcome many of these challenges, but some expressed reduced confidence in their ability to deliver optimal care during this time.[69]

The emotional impact of working with motor neurone disease. Many sources referenced the emotional involvement for professionals working with motor neurone disease.[22,24,26,37,38,40–42,45,46,52,55,56,58,64,68,73,76–78] A full overview of the emotional and psychological responses described are provided in Table 3. Professionals reported needing to disengage their personal feelings[38,64] and using compartmentalisation as a coping mechanism, whereby they avoided thinking about work situations outside of work, many felt they would not be able to continue in their role otherwise:[77]

> *I kind of have to separate a bit emotionally because obviously I wouldn't be able to survive*[77]

Other professionals, particularly those who spent a lot of time with patients such as clinical specialists, homecare nurses and primary care teams reported developing close relationships and for some an emotional connection or bond.[37,41,58] These professionals could feel profound loss on the patient's death.[41,58] In one source, 66% of neurologists and 94% of clinic managers contacted a patient's family after their death and 25% of neurologists and 55% of clinic managers attended patient funerals;[22] another neurologist reported:

> *I don't go to funerals, it's kind of like my line. I can be sad with the patient and the family all the way to their death, but I just can't go to a funeral a week. . . it's just too much for me*[77]

Professionals discussed how some cases affected them more than others, such as when the disease progressed quickly, or patients were younger.[40] Others found it emotionally challenging to witness patient and family suffering.[25,45] Professionals described how it could be hard to leave their jobs behind when they were not working[60] and that episodes from work could occupy their minds in their private lives.[40] In two sources professionals reported lack of preparation and education about how to manage the emotional and moral suffering they experienced from working with these patients.[51,82]

Five sources discussed the profound emotional intensity for professionals involved in withdrawing non-invasive ventilation.[26,38,55,56,58] Professionals reported a huge emotional strain planning for the withdrawal, '*it felt like setting a date for someone to die*'[56] and '*a personal sadness*' after the withdrawal had taken place.[38] In a study of UK doctors over half of the respondents rated the emotional challenge of withdrawing ventilation as 7/10 with over 20% rating this as 9/10 on the scale.[55] Three studies reported the lasting effects on professionals involved in this process with some reporting vivid memories that stayed with them for years after the event.[38,55,56]

Nine sources discussed a sense of job satisfaction and reward that professionals experienced from working with motor neurone disease patients.[22–24,40,45,46,56,77,79] Professionals described how they felt privileged to be in the position to support patients and families through a difficult time, help them when they '*needed it most*'[40,46,47,56,77] and felt appreciated by the level of gratitude they received.[40,46,77,78]

> *you really get so much in return, you know, when you are in the midst of all the hopelessness – you actually feel the appreciation or gratitude coming from the patient or the relative*[40]

In two sources professionals reported that a benefit of their work was that the life and death scenarios they encountered, gave them greater perspective and appreciation for their own personal lives.[40,77]

Discussion

Main findings

To the best of our knowledge, this is the first review that has comprehensively identified the available literature representing professionals' experience and the emotional and psychological impact of working with motor neurone disease. A total of 1692 professionals are represented, from 15 disciplines and 6 key healthcare settings. There are few examples of other conditions requiring intervention from this number of professionals and teams, within a typically short trajectory of illness.

From this review it is evident that working with motor neurone disease is distinctive and more stressful than other areas of practice. The care provided is intensive, time-sensitive and needs to be individualised for each patient and their informal support network. It is necessary to keep up with emerging knowledge and evidence, specialist skills, technology and aids to meet the evolving needs and expectations of patients and families.

Table 3. Emotional and psychological responses described by healthcare professionals in included sources.

Emotional or psychological response	Examples of quotations	Additional sources of reference
Stress	*I do find the rapid transition from living to dying aided by the removal of a life sustaining treatment and supported by respiratory and conscious level depressant drugs to be more stressful than most other areas of practice*[26] It adds real stress when people are clearly progressing, but then you're waiting for something to happen. And in the meantime, they're struggling until that happens. And by the time that thing happens, the thing you've requested is out of date. So, then you're asking for something else[51]	Aoun et al.,[36] Mitsumoto and Rabkin,[41] Phelps et al.,[55,56], Ushikubo et al.,[61] O'Brien and O'Brien,[64] and Cipolletta and Reggiani[76]
Anxiety	*I often perceive a sort of anxiety in wanting the advance treatment directives, especially some colleagues directly involved in some procedures. Something that aims more to compensate for the anxiety of being in an urgent clinical condition and not knowing what to do*[75] *One neurologist expressed "Having had a migraine after each MND clinic, feeling stressed and anxious about having so little to offer, I have gradually accepted the limitations of my skills and some confidence that assisting the patients honestly and empathetically, and not 'abandoning' them is of most value to most patients"*[36]	Faull et al.,[26] Gale,[50] Phelps et al.,[55,56] and Hennessey[77]
Burnout	*Dr A 'The one thing I want to emphasise is that working with these patients has always been hard.. in this line of work where every person with the disease will die eventually.. I feel like I'm here for the long haul and I want to pace myself, and I want to pace our team. It's important to recognise one's own vulnerability to burnout and to recognise signs of stress'*[41]	Hennessey[77]
Emotional Exhaustion	*Informants described a feeling of being "filled up" and "being emotionally exhausted" when they arrived home after work & how they needed some quiet time alone*[40] The emotional drain was enormous as we are so unused to having that much control over the timing and place of death[26]	Daneau et al.,[24] Faull et al.,[26] Erlen et al.,[43] Oliver and Turner,[52] Ushikubo et al.,[61] and Hennessey[77]
Burden	*We get so affected by it because it's so hopeless & the hopelessness it's such a heavy burden to carry*[60] *I guess in a way I'm just trying to take the burden from the patient and the caretaker and putting it on myself. And, um carrying that burden, it's very hard for me*[77]	Faull et al.,[26] Brown et al.,[37] Faull et al.,[38] Mitsumoto and Rabkin,[41] Phelps et al.,[55] Olesen et al.,[60] Ushikubo et al.,[61] Hennessey,[77] and Beyermann et al.[78]
Frustration	*Limitations inclusive of lack of personnel, time and equipment and the external economics which affected care delivery.. led to frustrations for the care professionals due to a limited ability to achieve their ideals of care*[37] *It's frustrating in a sense because we don't have a defined – a definitive treatment for them*[77]	Gamskjaer et al.,[40] Erlen et al.,[43] Hogden et al.,[51] Dengler and Troger,[53] Ushikubo et al.,[60] and Hennessey[77]
Loss	*Those who specialise in caring for patients with ALS often know their patients for longer than palliative care specialists. Thus, when a patient with ALS dies, the loss experienced by ALS professionals can be even more profound*[41]	
Privilege	*It is a humbling experience and a privilege to be part of so many courageous people's lives*[47] While it is not easy, each of these moments define why I consider myself incredibly privileged. I am able to help people when they need it most[46]	Gamskjaer et al.,[40] Hennessey,[77] Beyermann et al.,[78] and Kloos[79]

Developing trusting relationships with patients and families was seen as important as professionals frequently engaged in difficult and emotionally charged conversations about deteriorating health and future care planning. Complex decision-making also raised significant legal, moral and ethical uncertainty for many professionals involved.

Factors were identified which could restrict or support professionals to provide what they considered high-quality care. These included the physical and psychological condition of the patient, the needs of their informal caregivers, team and collegial support and a range of organisational factors. Three sources also discussed practical and emotional challenges to providing adequate care for this population during the COVID-19 pandemic. This is widely supported in the literature with many professionals experiencing mental health problems and moral injury because of difficulties delivering optimal care for severely unwell patients during this time.[81] Despite the added impact of COVID-19, the emotional and psychological toll for those working with motor neurone disease was evident before this period, with both positive and negative implications identified in this review.

What this study adds, implications for practice and future research

The findings of this review corroborate research outlining the difficulties experienced by motor neurone disease patients and informal caregivers in their interactions with the healthcare system. Their experience of services as being fragmented and difficult to access[12,82] is echoed by professionals in this review. Professionals identified geographical variation in services and funding available,[62] different team compositions and priorities,[13] poor communication between teams and services,[39] time pressures and varying degrees of professional confidence and experience[65] as limiting their ability to provide adequate levels of care in some circumstances. Feelings of powerlessness and frustration were expressed by professionals in several situations when they felt constrained in their ability to efficiently meet their patient's needs;[37,40,51,60] organisational factors were also attributable to experiences of stress and burnout.[22,51,77] Organisation-focussed changes and interventions have been shown to effectively reduce burnout for healthcare workers.[83] The need to standardise care pathways and inter-service communication among professional teams has been previously called for[84] and is required to alleviate the stress associated with poorly co-ordinated care for patients, their families and the healthcare teams involved.

The emotional toll for professionals exposed to repeated patient suffering, death and dying are well established in oncology and palliative care.[85,86] Previous research has identified the need for greater recognition of the emotional burden for professionals caring for people with terminal neurological diseases.[87] Harris et al.[21] found that professional well-being was almost completely ignored in the motor neurone disease literature, despite alluding to stress and burnout as a problem. Similarly, this review found that professional well-being was not directly questioned or measured and was not the primary aim of most identified sources. However, feelings of being overwhelmed, burdened, emotionally exhausted, frustrated, stressed, anxious and burnt-out were identified by professionals' managing different aspects of motor neurone disease patient care. The psychological well-being of healthcare professionals is a growing concern internationally.[88] Reduced professional well-being in many clinical areas, is linked to absenteeism, high rates of turnover and has implications for the quality of patient care.[89] Phenomena, such as occupational stress, burnout, compassion fatigue and moral distress have been widely recognised for clinicians faced with prolonged exposure to patient suffering, complex end-of-life care dilemmas[90,91] and for those working in high intensity clinical environments.[92,93] The challenges described by professionals in this review further strengthen the need to investigate the well-being of this population. Identifying specific risk factors for reduced professional well-being is important to mitigate the consequences for professional retention and motor neurone disease patient care.

It is important to highlight the positive experiences identified by professionals working with motor neurone disease, including feelings of pride and satisfaction in being able to help[46] and enhanced appreciation for their own health and personal lives.[77] Having good multidisciplinary team and collegial support was important for job satisfaction;[40] for those who were working alone feelings of stress and anxiety were more prominent.[56,76] This is concordant with the palliative care literature, whereby homecare assistants and community nurses providing hospice care at home identify loneliness and isolation as factors negatively influencing their job satisfaction. Peer support and contact positively impact their well-being and intention to stay.[94] Potentially protective or supportive factors were not explicitly measured in any identified source or explored with members of the multidisciplinary team, other than neurologists. Coping mechanisms, such as compartmentalisation and debriefing with colleagues were identified in one study.[77] Previous experience was helpful in certain circumstances,[60] but was not always the case. More years of experience could be associated with higher stress levels,[22] and years of experience was not helpful in the most challenging clinical scenarios.[35,49] Personal protective factors, meaning in work[95] resilience[96] and coping styles[97,98] have been identified as supporting professionals working in palliative and other end-of-life care positions and warrant greater consideration for those working with motor neurone disease.

This review identified that while professionals from different disciplines and working within different service and organisational structures share many of the same stresses, frustrations and emotional responses to working with this patient population, they also have different experiences, responsibilities and needs for support. Despite many sources recognising these differences, they were not explored in depth. To facilitate professionals to work synergistically and provide the level of integrated care required by motor neurone disease patients, future work is needed to identify both the individual and shared needs for support of the different groups of professionals involved in providing care for these patients.

Strengths and limitations

This is the first review to provide a comprehensive overview all healthcare professionals' experience and perspective of providing motor neurone disease care. The primary strength of this review is the use of a transparent, systematic and reproducible search strategy and broad inclusion criteria. Included sources were limited to the English language typically reflecting middle to high income countries such as the UK, USA and Australia. This may have excluded representation of healthcare services from other countries that may have provided alternative cultural insights or challenges. Some included sources can be considered low level evidence such as case reports and opinion pieces. Title and abstract screening were completed by the first author only. Although due care was taken, some relevant sources may have been excluded in error, as they were not cross-checked. Critical appraisal of included sources was not undertaken, as was not relevant for the purpose of this review.

Conclusion

By reviewing the literature available from 1990 to 2024, we have categorised how healthcare professionals describe the experience of working with those affected by motor neurone disease. Professionals perceive working with motor neurone disease as distinctive from other life-limiting conditions. External and organisational barriers could limit their ability to provide optimal levels of care and working with these patients and families had implications for professional well-being. The potential for some to remain working in this clinical area over time was questioned, while others avoided working with this patient group. Working within an effective and supportive multidisciplinary team was important for both job satisfaction and emotional support. Addressing some of the external and organisational issues identified has the potential to support and retain professionals to provide the intensive, integrated and specialist level of care required by these patients and their informal support network. It is also important to acknowledge and recognise the potential for professional stress and emotional burden for those interacting with these patients and their families. Future research should focus on identifying specific risk and protective factors for professional well-being and tailored support strategies to address the unique needs of professionals working with motor neurone disease.

Author contributions

MW developed the study protocol, completed the search process, extracted and analysed data and wrote the manuscript. AC reviewed the study protocol, assisted with the search process, reviewed, edited and approved the final version of the manuscript. DM developed the search strategy and assisted with the search process. MG reviewed the study protocol, assisted with the search process, reviewed, edited and approved the final version of the manuscript.

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