Psychological interventions for people with motor neuron disease: a scoping review

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Abstract

Objective: Motor neuron disease (MND) is a rapidly progressive neurodegenerative condition with no known cure. MND can affect every aspect of a person's life and has been associated with a wide range of psychological difficulties, which can occur from pre-diagnosis through to the condition's later stages. However, very little research has been conducted on psychological interventions for people with MND (pwMND). This paper aimed to provide the first review specifically targeting psychological interventions in MND, and offer potential directions for future research.

Methods: A scoping review was carried out across five major databases (PubMed, PsycINFO, CINAHL, Academic Search Ultimate, and Cochrane Library) until 1st of March 2020.

Results: From an initial return of 1278 citations, ten papers were included in the review. These included three randomised controlled trials (RCTs), two quasi-experiments, three uncontrolled pretest-posttest designs, one single case study, and one qualitative secondary analysis. The existing studies focused on a limited number of psychological outcomes and did not take into account site of MND onset or level of depression/anxiety before intervention. Implications for clinical practice are discussed and suggestions for future research are provided. Conclusions: The literature on psychological interventions is still extremely sparse. Mindfulness-based stress reduction (MBSR) and cognitive behavioural therapy (CBT) based on the stress-coping model show promise in RCTs but require further evaluation. The need for further development and evaluation of psychological interventions to improve the well-being of pwMND cannot be overstated, particularly as the struggle toward the discovery of an effective treatment for MND continues.

Keywords: motor neuron disease; amyotrophic lateral sclerosis; psychotherapy; clinical psychology; psychological interventions.

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Introduction

Motor neuron disease (MND), also known as amyotrophic lateral sclerosis (ALS), is a life-limiting neurodegenerative condition characterised by the progressive death of both upper and lower motor neurons (1). It affects about 2 in 100,000 people worldwide (2,3) and leads to weakening and wasting of muscles (up to complete paralysis), dysarthria, dysphagia, and severe respiratory impairment. The age of onset is typically between 50 and 70 (4), and the subsequent average life expectancy is three to five years. For most people with MND (pwMND), the disease begins with weakening in one of the limbs ('limb onset'; (5)), while about 30% of individuals show early swallowing and speech impairments ('bulbar onset'; (1)). As no cure is currently available (5,6), the clinical management relies mainly on symptomatic and palliative care, with the aim of maintaining or improving quality of life (7).

Psychological difficulties in pwMND

Since no specific test for MND is currently available, the diagnosis typically consists of multiple medical examinations aimed at excluding any mimicking conditions, which frequently translate into a long and uncertain path to diagnosis, lasting on average 10-18 months (4). This may, in turn, lead pwMND to experience high levels of anxiety and depression (8,9) and to develop coping strategies based on denial and avoidance (10–12), which can lead to poorer quality of life (13,14).

Even before diagnosis, the physical symptoms of MND and the way they are perceived socially can affect a person's independence, their roles and identity, confidence, and self-esteem. People with bulbar onset generally show higher levels of psychological distress (13,15), and research indicates that breathing, swallowing, and speech difficulties are associated with this distress (16). For example, dysarthria can impact psychosocial factors (17,18), leading to changes to perceived identity, feelings of self-consciousness, and negative emotions (19,20). Dysphagia has been linked to fear of choking (21–24), loss of pleasure deriving from eating (25–27), and loss of control (10,28–30). However, with the exception of fear of choking, many of these psychosocial and emotional consequences of physical symptoms would also apply to people with limb onset. In addition, regardless of onset type, symptoms are progressive, and many people eventually develop a combination of limb and bulbar symptoms (1). Therefore, the losses are cumulative and significant adjustment must continue throughout the course of the disease (7).

Moreover, around 40 to 50% of pwMND are estimated to experience some form of cognitive impairment – mainly involving executive functioning, language and verbal fluency (31,32) – and about 10-15% meet the full criteria for a diagnosis of frontotemporal dementia (33,34). As cognitive flexibility and flexible affective processing both represent predictors of trait resilience (35), cognitive impairments are likely to affect the emotional coping abilities of pwMND, as well as their response to psychological treatment.

In spite of the fact that recent qualitative evidence emphasised the need for tailored psychological approaches for pwMND (37,39), very little research has been conducted so far on the topic (36–38). One existing review that focused on both pharmacological treatments and psychological interventions concluded that evidence for the latter up to 2015 was too limited to provide any sensible clinical recommendations (38). However, very broad search terms were used for psychological interventions (e.g., 'psychological therapy' or 'counselling'), with none targeting specific types of therapy. Similarly, another review on multiple neurodegenerative conditions up to 2016 pointed out the lack of studies on psychological interventions in MND, but, due to its predominant focus on cognitive rehabilitation, it only included studies involving pwMND with cognitive impairment (40).

Thus, the aim of the present review was to focus specifically on psychological interventions in pwMND by adopting a more detailed and targeted search strategy and including different therapy models. In addition, it aimed to include any papers published since the mid 2010s.

Materials and methods

Methodological approach

A scoping review was carried out, based on the guidelines by the Joanna Briggs Institute (41). This approach was adopted since it specifies a replicable database search without the need for a narrower question, which would have been incompatible with the current paucity of literature (36–38,42,43).

Inclusion criteria

To be included, studies had to a) be related to pwMND; b) involve individuals aged 18 or above; c) describe the delivery of any form of psychological intervention with pwMND. Interventions targeting caregivers as well were included as long as the data for pwMND could be extracted. Qualitative designs were considered eligible if they related to a form of intervention. Studies not adhering to the inclusion criteria, reviews, commentaries, protocols, editorials, and letters were excluded.

Quality assessment

Since a formal quality appraisal is not typically performed in scoping reviews (41,44), this was not included in the present review. However, efforts were made to point out

methodological and clinical limitations whenever present.

Procedure

A combination of free text terms was adopted to search Academic Search Ultimate, CINAHL, Cochrane Library, PsycINFO, and PubMed up until 1st March 2020. Reference lists of included studies were hand-searched. Table 1 shows the logic grid for the search strategy, while Table 2 illustrates the adopted search terms.

Initially, one reviewer (NZ) screened all titles and abstracts against the inclusion criteria. The full-text of the remaining citations were then screened by another reviewer (FE) and confirmed by a third reviewer (JS). Figure 1 illustrates the PRISMA flow diagram of the study selection. The final data extraction was performed independently by two reviewers (NZ, FE), and double-checked for accuracy by further two reviewers (EM, NOS).

Results

The initial search across the databases returned a total of 1278 studies, which were narrowed down to 764 after filtering and deduplication. Titles and abstracts were then screened thoroughly, and a total of 14 articles remained for full-text screening. Eventually, 10 studies were included. These were three randomised controlled trials (RCTs), two quasi-experiments, three uncontrolled pretest-posttest designs, one single case study, and one qualitative secondary analysis. Table 3 summarises the key characteristics and results of the eligible studies, while Table 4 lists the excluded fulltexts along with the rationale for exclusion.

Randomised controlled trials

Averill and colleagues (45) carried out an RCT to compare the effect of expressive

disclosure on psychological well-being of pwMND compared to no psychological treatment. Although measures of affect, depression, and quality of life were adopted, an *ad-hoc* composite well-being measure consisting of the mean of the standardised scores was used for the main analysis. The results showed that the intervention group had significantly higher levels of well-being compared to controls at three months (i.e., post-intervention). Interestingly, ambivalence over emotional expression was found to mediate the effect of intervention on well-being, with participants in both groups who had higher ambivalence over emotional expression who participated in the intervention had improved well-being at three months, whereas those in the control group had decreased well-being. The benefits of expressive disclosure were not maintained at six months.

Pagnini et al. (46) evaluated an 8-week MND-specific meditation programme based on mindfulness-based stress reduction (MBSR; (47)) in comparison with treatment as usual. The results showed significant improvements for levels of anxiety, depression, and quality of life immediately post-intervention, as well as at 6- and 12months follow-up. In addition, a secondary qualitative analysis of the same study (48) was carried out adopting grounded theory and reported that the participants believed the intervention had a positive impact on their psychological well-being, promoted by an increase in acceptance and a non-judgmental attitude.

Van Groenestijn et al. (49) designed a CBT intervention based on the stresscoping model consisting of six modules specifically tailored to pwMND and their caregivers. However, the RCT had to stop prematurely due to difficulties with recruitment. The analysis of the preliminary data showed significantly less deterioration in mental quality of life in the intervention group when compared to controls receiving treatment as usual.

Other designs

Díaz et al. (50) delivered a 4-session CBT programme combined with counselling techniques, and compared it to treatment as usual in a quasi-experiment. Assessments were only carried out at baseline and post-intervention. In the intervention group the results showed a significant decrease in the proportion of participants with moderate and severe anxiety (from 63.3% to 16.7%) and those with moderate and severe depression (from 36.7% to 10.0%). No significant changes were observed in the control group.

Palmieri et al. (51) adopted an uncontrolled pretest-posttest design with pwMND to pilot a psychodynamic hypnosis 4-week intervention combined with domiciliary visits and self-hypnosis training. At post-intervention, the results showed a significant decrease in anxiety and depression, as well as lower negative affect and higher spirituality components of quality of life. The same intervention was later evaluated with a quasi-experimental design (52) which enrolled one-by-one matched controls with MND. The findings were consistent with the pilot, showing improvements in psychological outcomes immediately after the treatment, improvements in anxiety maintained at 3- and 6-month follow-up.

Aoun et al. and Bentley et al. (53,54) reported on the same uncontrolled pretestposttest feasibility study conducted to evaluate dignity therapy (DT) with pwMND and their caregivers. The results at post-intervention showed that, while DT was well received by the participants – including those who required augmentative and alternative communication (ACC) – no significant differences were observed in quality of life for either pwMND or their caregivers. Finally, García Pérez and Dapueto (55) reported a single case of computerassisted psychotherapy (using ACC) with a 66-year-old woman with MND. The intervention was based on cognitive-behavioural and expressive-supportive models and techniques, and reportedly led to decrease in psychological distress and increased symptom control, communication, autonomy, dignity, and self-esteem. ACC was reported to work well in combination with the computer-assisted intervention. However, no quantitative data were provided to evidence these findings.

Discussion

To our knowledge, the present review was the first to target studies on psychological interventions with pwMND. While the detailed search strategy and fiveyear interval since the only two more general reviews available (38,40) generated five additional citations, doubling the total, this has still only brought the number of studies to ten. In addition, only three (45,46,49) were randomised control trials (RCTs), while the remaining were mainly quasi-experimental and uncontrolled designs. The current literature also neglects important aspects of psychological distress. Therefore, more research into psychological approaches to improve the emotional well-being and quality of life for pwMND is urgently required. In particular, as the current evidence base mainly consists of small *n* and low powered investigations, further research should focus on building on these by enrolling larger and sufficiently powered samples (possibly across multiple locations) as well as adopting more empirically robust methods such as RCTs.

Nevertheless, it is encouraging to see that all of the studies report either maintenance or improvements in psychological outcome variables (where these are measured), and that participants found the interventions acceptable. Therefore, the initial indications are that psychological interventions are unlikely to be harmful and have the potential to be helpful. However, the very limited number of studies means that the evidence is insufficient to make clear recommendations about which specific therapy models are most effective for specific problems. In fact, the literature to date suggests that multiple therapy models could be useful, either targeting similar or distinct aspects of psychological distress/well-being (46,49,52).

The discussion section will attempt to focus on four major psychological challenges frequently associated with MND, namely anxiety and depression, emotional difficulties, and quality of life. However, given the very limited evidence available, these results should be interpreted cautiously.

Anxiety and depression

Anxiety and depression represent two of the most common psychological difficulties in pwMND, with estimates reaching up to 44% and 30% of affected individuals respectively (56), but have been the subject of only one RCT (46). This study, using a tailored form of MBSR, has shown positive and long-lasting beneficial reductions in levels of anxiety and depression. One further RCT (45) reported positive results for the adoption of expressive disclosure by using a psychological well-being composite score. However, the specific effect on depression was unclear.

Preliminary evidence from quasi-experimental and uncontrolled designs also suggests promising results for CBT with counselling techniques (50) and psychodynamic hypnosis (51,52) on anxiety and depression. Anecdotal benefits have also been reported for computer-assisted CBT with expressive-supportive techniques in the treatment of anxiety specifically.

Emotional difficulties

Difficulties with emotions are commonly observed in pwMND (57), and may include

deficits in emotion perception and emotion regulation, including emotional lability (10,58–61). These kinds of difficulties are thought to be due to a combination of psychological adjustment to the condition (10,62) and potential underlying frontal cognitive deterioration (58). However, to date no psychological intervention study has specifically targeted difficulties with these aspects of emotion in pwMND. The only preliminary evidence currently available comes from an RCT adopting expressive disclosure and suggesting that ambivalence over emotional expression may mediate the effect of the intervention on well-being (45). It is unclear whether these results focused on ambivalence would translate to people experiencing difficulties with emotion perception or emotion regulation.

Quality of life

Due to MND's rapid progression and the lack of treatment options (1), the maintenance or improvement of quality of life currently represents the mainstay of clinical management (7). The importance of psychological interventions is underpinned by evidence suggesting that psychological difficulties are stronger predictors of poor quality of life than the physical impairments caused by the disease (63–66).

To date only two RCTs (46,49) have explored interventions to address quality of life specifically, showing benefits for MND-tailored MBSR (corroborated by a secondary qualitative analysis (48)) and possibly CBT. A third RCT (45) found a positive short-term (i.e., three months) effect of expressive disclosure on a psychological well-being composite score. However, the impact of this intervention specifically on quality of life remains unclear.

Less rigorous findings available from quasi-experimental and uncontrolled designs showed promising preliminary evidence for treatments based on psychodynamic hypnosis combined with domiciliary visits and self-hypnosis training sessions (51,52), while no changes were observed when adopting DT (53,54).

Clinical implications and future directions

The results of the present review show that our understanding of whether psychological interventions are effective for pwMND is still extremely limited. According to the data available to date, MND-tailored MBSR (46,48) has the strongest evidence base for improving anxiety, depression, and quality of life. While this represents a promising start, it is still far too early to be certain that this is the best possible psychological intervention. In addition, more research is required to assess the efficacy of other approaches, including psychodynamic hypnosis (51,52) and CBT based on the stress-coping model (47) or combined with counselling techniques (50).

Interestingly, all but one of the approaches that have shown promise in MND to date include elements of CBT, either directly or in the principles underpinning them. MBSR is one of a number of 'third wave' interventions that grew from CBT and include a focus on mindfulness. Acceptance and commitment therapy (ACT) is another approach that has not yet been evaluated in MND, but appeared promising in other health and palliative care settings (67,68). Therefore, further research on these approaches interventions would be particularly relevant, as they also have the additional advantage of already being widely available (69,70), which would facilitate their adoption in other clinical areas. It is also possible that existing manualised forms of face-to-face and internet-based CBT could be adapted specifically for people with MND (69).

A number of limitations were evident in all the studies included in this review. Firstly, as mentioned above, some of the results were characterised by low levels of methodological robustness – such as non-randomised (50,52) uncontrolled (51,53,54), or

single case (55) designs – or inadequate reports of finding (e.g., no quantitative data available for (55)). Secondly, despite evidence that bulbar onset MND is associated with higher levels of depression and anxiety (13,15,16), none of the studies differentiated between site of onset in reporting their results. In addition, few studies reported whether participants with MND showed clinically significant levels psychological distress prior to the interventions and - even when these were reported the increased variability due to the adoption of assessment tools based on different methodologies (e.g., semi-structured interviews v. self-report questionnaires; (71)) should be taken into account when pooling the results. Considering that clinical services would generally only receive referrals for people experiencing levels of psychological difficulties high enough to be classified as 'clinical' on standardised measures, it is important to understand the effectiveness of these interventions on people experiencing clinically significant depression or anxiety, as well as potentially understanding its effect in people not reaching these thresholds. Interventions building resilience as opposed to targeting specific symptoms might also be useful given the varied and fluctuating nature of the psychological challenges (72).

The current literature, although limited, suggests that psychological interventions could augment usual clinical care, which includes important support and information already offered by non-psychology healthcare professionals and third sector volunteers. Therefore, future MND research focused on further development and evaluation of psychological interventions is strongly warranted. In particular, when developing interventions, attention should be paid to the psychosocial, emotional, and physical changes that can occur in pwMND to ensure that the approach is relevant and acceptable. When evaluating interventions, attention should be paid to participants' levels of distress at the beginning of therapy, site of MND onset, emotional perception and regulation difficulties (10,58–61), psychosocial issues (65,73,74), cognitive and behavioural change (75), and loss of perceived control (10,28–30). It would also be helpful for studies to identify the proposed mechanisms of change that affect outcomes (e.g., alliance, behaviour change, present moment focus) and include consideration of which psychological outcomes are being targeted (e.g., anxiety, depression, quality of life, or other). Building on this, the direct comparison of the effectiveness of different types of therapies would be desirable, again keeping in mind how clinical and baseline psychological variables could interact with treatment approach.

Ultimately, as the struggle toward the discovery of an effective treatment for MND continues, the need for psychological interventions to increase the psychological well-being and quality of life of people with MND cannot be overstated.

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Tables

Population	Interventions				
Motor neuron* disease	Acceptance and commitment therapy Behavio* therapy	Motivational interviewing			
Amyotrophic lateral	Cognitive analytic therapy	Narrative therapy			
sclerosis	Cognitive behavio* therapy	Person cent* therapy			
	Cognitive therapy	Psychoanal*			
	Compassion* focused therapy	Psychodynamic therapy			
	Counsel*	Psychoeducati*			
	Couple* therapy	Psychological intervention			
	Dialectical behavioral therapy				
	Emotion focused therapy	Psychotherap* Rational emotive			
	Emotive behavio* therapy	behavio* therapy			
	Eye movement desensiti* and	Schema therapy			
	reprocessing	Self-management			
	Family therapy	Solution focused			
	Gestalt therapy	therapy			
	Group* therapy	Systemic therapy			
	Integrative therapy				
	Interpersonal therapy				
	Meditat*				
	Metacognitive therapy				
	Mindfulness				
	Mindfulness-based cognitive therapy				
	Mindfulness-based stress reduction				

Table 1. Logic grid for search strategy.

Table 2. Overview of adopted search terms and identified items per database.

Search terms

(Motor neuron* disease AND Acceptance and commitment therapy) OR (Motor neuron* disease AND Behavio* therapy) OR (Motor neuron* disease AND Cognitive analytic therapy) OR (Motor neuron* disease AND Cognitive behavio* therapy) OR (Motor neuron* disease AND Cognitive therapy) OR (Motor neuron* disease AND Compassion* focused therapy) OR (Motor neuron* disease AND Counsel*) OR (Motor neuron* disease AND Couple* therapy) OR (Motor neuron* disease AND Dialectical behavioral therapy) OR (Motor neuron* disease AND Emotion focused therapy) OR (Motor neuron* disease AND Emotive behavio* therapy) OR (Motor neuron* disease AND Eve movement desensiti* and reprocessing) OR (Motor neuron* disease AND Family therapy) OR (Motor neuron* disease AND Gestalt therapy) OR (Motor neuron* disease AND Group* therapy) OR (Motor neuron* disease AND Integrative therapy) OR (Motor neuron* disease AND Integrative therapy) OR (Motor neuron* disease AND Meditat*) OR (Motor neuron* disease AND Metacognitive therapy) OR (Motor neuron* disease AND Mindfulness) OR (Motor neuron* disease AND Mindfulness-based cognitive therapy) OR (Motor neuron* disease AND Mindfulness-based stress reduction) OR (Motor neuron* disease AND Motivational interviewing) OR (Motor neuron* disease AND Narrative therapy) OR (Motor neuron* disease AND Person cent* therapy) OR (Motor neuron* disease AND Psychoanal*) OR (Motor neuron* disease AND Psychodynamic therapy) OR (Motor neuron* disease AND Psychoeducati*) OR (Motor neuron* disease AND Psychological intervention) OR (Motor neuron* disease AND Psychotherap*) OR (Motor neuron* disease AND Rational emotive behavio* therapy) OR (Motor neuron* disease AND Schema therapy) OR (Motor neuron* disease AND Self-management) OR (Motor neuron* disease AND Solution focused therapy) OR (Motor neuron* disease AND Systemic therapy)

(Amyotrophic lateral sclerosis AND Acceptance and commitment therapy) OR (Amyotrophic lateral sclerosis AND Behavio* therapy) OR (Amyotrophic lateral sclerosis AND Cognitive analytic therapy) OR (Amyotrophic lateral sclerosis AND Cognitive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Cognitive therapy) OR (Amyotrophic lateral sclerosis AND Compassion* focused therapy) OR (Amyotrophic lateral sclerosis AND Counsel*) OR (Amyotrophic lateral sclerosis AND Couple* therapy) OR (Amyotrophic lateral sclerosis AND Dialectical behavioral therapy) OR (Amyotrophic lateral sclerosis AND Emotion focused therapy) OR (Amyotrophic lateral sclerosis AND Emotive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Eye movement desensiti* and reprocessing) OR (Amyotrophic lateral sclerosis AND Family therapy) OR (Amyotrophic lateral sclerosis AND Gestalt therapy) OR (Amyotrophic lateral sclerosis AND Group* therapy) OR (Amyotrophic lateral sclerosis AND Integrative therapy) OR (Amyotrophic lateral sclerosis AND Interpersonal therapy) OR (Amyotrophic lateral sclerosis AND Meditat*) OR (Amyotrophic lateral sclerosis AND Metacognitive therapy) OR (Amyotrophic lateral sclerosis AND Mindfulness) OR (Amyotrophic lateral sclerosis AND Mindfulness-based cognitive therapy) OR (Amyotrophic lateral sclerosis AND Mindfulness-based stress reduction) OR (Amyotrophic lateral sclerosis AND Motivational interviewing) OR (Amyotrophic lateral sclerosis AND Narrative therapy) OR (Amyotrophic lateral sclerosis AND Person cent* therapy) OR (Amyotrophic lateral sclerosis AND Psychoanal*) OR (Amyotrophic lateral sclerosis AND Psychodynamic therapy) OR (Amyotrophic lateral sclerosis AND Psychoeducati*) OR (Amyotrophic lateral sclerosis AND Psychological intervention) OR (Amyotrophic lateral sclerosis AND Psychotherap*) OR (Amyotrophic lateral sclerosis AND Rational emotive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Schema therapy) OR (Amyotrophic lateral sclerosis AND Self-management) OR (Amyotrophic lateral sclerosis AND Solution focused therapy) OR (Amyotrophic lateral sclerosis AND Systemic therapy)

Citation	Design	Sample	Intervention	Psych. outcome	Key results
(45)	RCT	l: 24 C: 24	Expressive disclosure	Emotional difficulties	Significantly higher well-being in intervention group at 3 months, but not post intervention or 6 months. Mediation role of ambivalence over emotional expression (AEE) at 3 months.
(46)	RCT	l: 50 C: 50	Mindfulness-Based Stress Reduction protocol (modified for ALS)	Anxiety Depression QoL	Significant differences between groups at post-intervention for depression, anxiety, negative emotions, QoL, and social interaction.
					Differences maintained at 6- and 12-months follow-ups.
(48) Qualitative (secondary analysis of (46	Qualitative (secondary analysis of (46))	26)	26 Meditation based on Mindfulness-based Stress Reduction protocol (modified for ALS)	Anxiety Depression QoL	Patients improvement in coping with anxiety and depression, in sleep problems, mindfulness skills, and QOL.
					Overall positive impact of intervention on psychological well-being, as well as increase in acceptance and non-judgmental attitude.
(49)	RCT (nested in larger study)	I: 10 CBT intervention based on stress-coping model	QoL	Study ended prematurely due to slow recruitment.	
					Preliminary significant difference between groups on mental QoL (primary outcome).
					No differences on psychological distress (secondary outcome).

Table 3. Key characteristics of included studies.

(50)	Quasi-experiment	I: 30	CBT with counselling techniques	Anxiety	Significant improvements at post-intervention in both anxiety and depression for intervention group.
		C: 24		Depression	
					No significant differences in either anxiety or depression for control group at post- intervention.
(51)	Uncontrolled pre-post	8	Psychodynamic hypnosis-based treatment	Anxiety	Significant improvements in depression,
				Depression	anxiety, quality of life.
				QoL	Qualitative reports of improvements in pain, sleep, emotional lability, fasciculation syndrome.
(52)	Quasi-experiment	I: 15	Psychodynamic hypnosis-based treatment	Anxiety	Significant improvements in depression,
		C: 25		Depression	anxiety and QoL at post-intervention for the intervention group.
				QoL	Improvements in anxiety maintained at 3- month and 6-month follow-ups.
(53)	Uncontrolled pre-post	27	Dignity therapy	QoL	Dignity therapy well accepted by patients, including those who require assisted communication devices. Feasibility may be limited in small or not well-resourced services.
					No significant differences in all outcome measures for both groups.
(54)	Uncontrolled pre-post	29	Dignity therapy	QoL	Dignity therapy acceptable to people with MND (based on feedback questionnaires) if communication issues are overcome.

					No significant differences in outcome measures at group level. QoL not formally measured as outcome.
(55)	Single case	1	Computer-assisted CBT	Anxiety	No quantitative data provided.
			with expressive- supportive techniques		Reportedly better symptom control, improved communication with the team and family, reduction of psychological distress, and promotion of autonomy, dignity, and self- esteem.
					Good acceptability of combination of augmentative and alternative communication (AAC) with psychotherapy.

Note. C = control; I = intervention.

Table 4. Articles excluded following full-text review.

Study	Design	Type of intervention	Reason for exclusion
(76)	Uncontrolled pre-post	Mindfulness based interventions	No specific results reported for pwMND
(77)	RCT	Meditation based on Mindfulness-based Stress Reduction protocol (modified for ALS)	Research protocol only (see (46)
(78)	Qualitative	N/A	Not including pwMND (interviews only with therapists)
(79)	RCT	CBT intervention based on stress-coping model	Research protocol only (see (49)



