



RESEARCH ARTICLE

# Targeting mindfulness interventions for people affected by motor neurone disease: consideration of the influence of baseline distress on psychological outcomes

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## ABSTRACT

**Aims:** This study of people with motor neurone disease (MND) and caregivers examined how baseline levels of psychological distress influenced engagement with and psychological responses to a mindfulness intervention. This was with a view to guiding how services can best target mindfulness programs.

**Methods:** Forty participants completed an MND-adapted four-session mindfulness-based stress reduction intervention, the 'MindfulMND' program. Participants were stratified into high and low distress groups with the Depression subscale of the MND-adapted Hospital Anxiety and Depression Scale (M-HADS). To examine engagement with the intervention, we compared session attendance and mindfulness practice frequency in the high and low distress groups. To examine psychological responses to the mindfulness intervention, we used a single arm waitlist design with assessments at pre-waitlist, pre-intervention, post-intervention and 1-month follow-up. Measures examined psychological distress, quality of life, positive psychological adjustment (benefit finding and post-traumatic growth) and mindfulness.

**Results:** Forty participants completed the program, with baseline stratification yielding high distress (n=11) and low distress (n=28) groups. Both groups had excellent attendance and engaged well with mindfulness practice, with different patterns of practice over time (percentage of participants per group practicing  $\geq 4$  times per week during fortnights 1, 2, and 3, respectively: high distress group- 91%, 72%, 66%; low distress group- 77%, 91%, 87%). In the high distress group, pre-post intervention comparisons showed improvements with large effects on measures of psychological distress (Demoralization, Perceived Stress and M-HADS Anxiety scales), quality of life (Global Life Satisfaction item, The Amyotrophic Lateral Sclerosis Specific Quality of Life Instrument-Revised), and positive psychological adjustment (Benefit-Finding Scale). Improvements in psychological adjustment were not evidenced in the low distress group.

**Conclusions:** Where resources are stretched, targeting mindfulness programs towards MND patients and carers with higher levels of distress may yield the greatest measurable clinical benefit. Screening tools such as the M-HADS may assist in the allocation of psychological services to those affected by MND. It is recommended that mindfulness interventions are modified to support access and engagement for people affected by MND.

**Keywords:** Motor neurone disease, depression, quality of life, caregivers, mindfulness, psychological intervention, group program

## 1. Introduction

People with MND (pwMND) face a lifespan of two to five years from symptom onset<sup>1,2</sup> with progressive disability and losses to work, domestic and leisure activities. There is uncertainty about the timing and nature of disease progression, and a need to consider interventions to support basic functioning (e.g., communication, mobility) and to sustain life (e.g., percutaneous endoscopic gastrostomy, non-invasive ventilation). Independence is eroded which leads to increased dependence on others, often for basic personal care tasks. Such changes also impact family members who, in concert, gradually take on the weight of household management and ever-increasing direct caregiving tasks. This is on top of the emotional impact of witnessing the person with motor neurone disease (MND) deteriorate, and anticipatory grief related to their early death.

Understandably, a proportion of pwMND and their family members experience clinically significant psychological distress, including anxiety, depression and feelings of hopelessness.<sup>3,4</sup> For example, a review of 46 studies of pwMND showed the average pooled prevalence of depressive symptoms was 34%<sup>5</sup> and questionnaire studies of anxiety have shown rates of up to 30%.<sup>6,7</sup> In caregivers, rates of depression and anxiety have been estimated as 23% and 16% respectively.<sup>8</sup> Depression and anxiety in pwMND can contribute to a range of deleterious outcomes, such as poor quality of life,<sup>3,9</sup> longer hospital admissions,<sup>10</sup> risk of suicide,<sup>11</sup> higher caregiver burden,<sup>12</sup> and potentially higher levels of disability and earlier mortality.<sup>13</sup> For caregivers, higher levels of depression and anxiety have been associated with caregiver burden and poor quality of life, as well as earlier residential care placement for the person with MND.<sup>4,12,14</sup>

To assist in reducing psychological distress in MND, several psychological interventions have been trialled.<sup>15-17</sup> Particularly encouraging evidence has been shown for structured mindfulness based interventions, such as mindfulness-based stress reduction (MBSR).<sup>17</sup> A randomised controlled trial (RCT) of 100 pwMND showed significant post-MBSR improvements in depression, anxiety and quality of life, when compared with a treatment as usual control group.<sup>18</sup> A related qualitative study highlighted experiences of improved psychological well-being, acceptance and coping for pwMND as well as their caregivers.<sup>19</sup> In a further RCT of pwMND and caregivers a non-meditative mindfulness approach (focusing on present-centred awareness in daily life rather than on formal mindfulness practices) led to improved mood and quality of life for both groups.<sup>20</sup> The efficacy of mindfulness for MND is in line with the well-established psychological benefits of mindfulness shown over decades for a broad range of illnesses.<sup>21,22</sup> Mindfulness interventions are 'strongly recommended' for progressive neurological disorders under the GRADES evidence framework.<sup>23</sup>

With encouraging evidence for the efficacy of mindfulness for those affected by MND,<sup>17</sup> there is need to progress our understanding of how this intervention might best be implemented within services. Financial

resources, and therefore clinical resources, are typically stretched, and it is important to discern not only which interventions are most effective, but for whom.<sup>24</sup> A consistent finding in the oncology literature is that those with higher levels of distress at baseline show stronger responses to psychological interventions.<sup>25-27</sup> In a recent single arm study of those with new-onset MND, a brief (10 day) mindfulness intervention was shown to reduce depression and anxiety amongst those diagnosed with depression but not those without.<sup>28</sup> This study used only measures of psychological distress (depression, anxiety and stress), which may be subject to floor effects in patients with lower distress levels. Cafarella (2023, 2024) has highlighted the importance of including eudaimonic measures of wellbeing in studies of MND psychological interventions, which incorporate positive aspects of wellbeing like self-realisation and growth.<sup>16,29</sup> This may be particularly needed when considering participants with lower levels of distress, where questionnaires assessing hedonic wellbeing (such as measures of anxiety and depression) may not have adequate sensitivity to change. For those with lower levels of psychological distress, it is therefore not yet known whether they would find benefit in learning mindfulness over and above their existing coping strategies.<sup>17</sup>

Our mindfulness program, 'MindfulMND', was adapted for people affected by MND from the standard mindfulness based stress reduction (MBSR) protocol.<sup>30,31</sup> We set out to stratify participants according to low and high distress at baseline, and then to compare how these groups (i) engaged with the mindfulness intervention, based on session attendance and completion of home practice, and (ii) benefited from the mindfulness intervention, based on responses to measures of psychological adjustment. This was an exploratory study incorporating assessments of psychological adjustment extending beyond psychological distress and quality of life to include positive psychological adjustment, i.e., benefit-finding and post-traumatic growth.

## 2. Methods

### 2.1 PARTICIPANTS

Potential participants with early- to mid- stage MND were identified from our specialist multidisciplinary MND clinic, Calvary Health Care Bethlehem (CHCB), Melbourne, Australia. Exclusion criteria included: communication difficulties that would limit group participation (i.e., less than 100% intelligible or not speaking English), slow progressing variants of MND (primary lateral sclerosis, Kennedy's disease, flail arm MND), a major psychiatric illness, suspected frontal temporal dementia or other dementia, current routine practice of mindfulness, and living >2 hours away from the service.

We initially aimed to recruit 40 pwMND and caregiver dyads (n=80), anticipated to be appropriate to detect mild to moderate effect sizes.<sup>32</sup> Of 1084 files reviewed during the 2½ year recruitment period, 171 patients fulfilled the inclusion criteria and were invited to participate in the MindfulMND program, alongside their nominated family member/support person. Potential

participants were initially approached via the clinic nurse, neurologist or directly by the research team. Informed consent was obtained from all participants prior to their participation in the study. Study approval was obtained by the CHCB Research Ethics and Ethics Committee, research application number 18122002. Participants accessed the usual multidisciplinary services within CHCB throughout their participation, including approaches to support emotional wellbeing where necessary (e.g., clinical psychology, pastoral care, music therapy).

## 2.2 STUDY DESIGN AND MEASURES

Participants were stratified into high and low distress groups based on their responses to the Depression subscale of the MND adaptation of the Hospital Anxiety and Depression subscale (M-HADS<sup>33</sup>). The presence of depressive symptoms was selected to represent psychological distress as depression is a common psychological outcome assessed in MND studies<sup>4,18,20</sup> with a strong relationship to other dimensions of psychological adjustment (such as anxiety and quality of life) and to functional outcomes (e.g., level of disability, adherence with treatments).<sup>3,9-12</sup>

A cut-off score of  $\geq 5$  on the M-HADS Depression subscale was considered an indicator of depressive symptoms (high distress), as per the Rasch analysis conducted by Gibbons et al.<sup>34</sup> Once stratified, the high and low distress groups were characterised by comparing the groups on other dimensions of psychological adjustment at baseline. The demographic and disease-related characteristics of the two groups were also examined, with the telephone-administered Amyotrophic Lateral Sclerosis Functional Rating Scale Revised (ALSFRS-R)<sup>35,36</sup> providing an indication of functional impairment.

To examine how the high and low distress groups engaged with the MindfulMND program (Aim I), we prospectively tracked (i) participant session attendance and (ii) frequency of between-session mindfulness practice. Mindfulness practice was captured with the with the 12-item Mindfulness Adherence Questionnaire (MAQ).<sup>37,38</sup> We adjusted this measure to enable participants to provide specific details of the number of formal practice sessions each week based on response options (rather than an open ended question). The MAQ was completed prior to each session (apart from session 1).

To examine potential psychological effects of the MindfulMND program for participants with high vs. low distress (Aim II), a single arm waitlist design was employed. Assessments were conducted at pre-waitlist (T1), pre-intervention (T2), post-intervention (T3) and 1-month follow-up (T4). Measures of psychological adjustment assessed psychological adjustment difficulties, quality of life, positive psychological change and mindfulness, and are presented in Table 1. These were completed at each time-point using a secure online survey platform, Qualtrics.

## 2.3 PROCEDURE

Adaptations of the standard MBSR protocol<sup>30,31</sup> were made to increase the accessibility and meaningfulness of the program to those affected by MND (see Table 2 for

an overview of program content). Detailed facilitator and participant manuals of the MindfulMND program were developed. To reduce the physical and time demands of attending a face-to-face program, the number of sessions was decreased from eight weekly sessions, as per typical MBSR, to four fortnightly sessions. Prior research has supported the efficacy of a similarly reduced number of sessions in improving psychological adjustment in clinical groups.<sup>39,40</sup> To accommodate MND-related barriers to regular attendance, such as health complications and mobility and transport challenges, participants who were unable to attend a session (e.g., due to ill health) were offered a 'make-up' session via phone or video consultation with a facilitator. This adjustment is consistent with the identified need for a flexible approach to sessions for pwMND.<sup>41</sup>

As per standard MBSR, the essential focus of the MindfulMND program was on the core formal mindfulness practices (the body scan, mindfulness of breathing). Specific guidance was provided for managing breathing difficulties if these were occurring (i.e., to try observing this experience and, if needed, to change attentional focus) and mindful yoga was not taught due to mobility changes. The content of the MindfulMND program was necessarily abbreviated due to the shorter length of the program. In adjusting the content, sessions were adapted to enable discussion about the relevance of mindfulness to the experience of MND, with a view building mindfulness skills which were particularly relevant to coping with MND (e.g., responding versus reacting in response to stress, mindfulness practices to assist with difficult emotions). Between sessions, participants were requested to complete formal mindfulness practices, as well as informal mindfulness practices focusing on applying mindfulness to routine tasks (e.g., presence-centred awareness while having a cup of tea).

The MindfulMND program was conducted by clinical psychologists and neuropsychologists with experience in working with pwMND and delivering mindfulness interventions.<sup>42</sup> Five iterations were conducted across a two-year period, with the number of participants ranging from 5 to 12 in each. Face-to-face sessions ran for two hours with a tea break. All sessions were planned to occur face-to-face, however due to the COVID-19 pandemic, program delivery transitioned to an online platform mid-way through the third group and this approach continued for the fourth and fifth groups. Based on the experience of running the initial online program, sessions were conducted over 2.5 hours in the final online group to ensure coverage of all material and more time for group interactions and discussions in break-out rooms.

## 2.4 STATISTICAL ANALYSES

Given the small sample size, data for pwMND and caregivers were combined for statistical analyses. Pearson correlations were conducted to examine how the high versus low distress categorisation, based on the M-HAD Depression Scale, mapped onto (i) measures of psychological adjustment and (ii) demographic and disease characteristics.

The first aim, involving comparison of the high versus low distress groups according to their engagement with the

MindfulMND program, was examined using descriptive statistics. Specifically, we investigated the frequency with which the high versus low distress groups attended sessions and participated in between-session mindfulness practice (MAQ).

To examine the second aim, pertaining to the effects of the MindfulMND program on psychological adjustment in the high versus low distress groups, we examined changes in psychological adjustment variables over the waitlist (T1 vs. T2), intervention (T2 vs. T3) and follow-up (T2 vs. T4) comparisons using Wilcoxon signed rank test planned comparisons. The Wilcoxon analysis was selected due to

violations in normality and homogeneity of variance assumptions, which dictated the use of a non-parametric approach. We focused on effect sizes rather than statistical significance due to the exploratory nature of the study and small sample size. Effect sizes were calculated based on the approach recommended by Fritz and colleagues<sup>43</sup> where 0.1, 0.3 and 0.5 are considered as small, medium and large effect sizes, respectively. Corrections to adjust probability values were not calculated because this was an exploratory study using simple statistics and the results of each test were of importance.<sup>44,45</sup>

**Table 1:** Psychological measures

Area of Assessment and Measure	Description
<b>Psychological adjustment difficulties</b>	
I. The M-HADS Anxiety subcale <sup>33</sup>	I. This adaptation of the HADS omits items related to psychomotor activity and has been validated for clinical and research use for patients with MND. <sup>34</sup>
II. The Demoralization Scale <sup>46</sup>	II. The Demoralization Scale assesses elements of existential distress including loss of meaning, hopelessness and helplessness, and has been shown to be distinct from depression. Previous studies have indicated that demoralisation is an important dimension to assess in MND populations. <sup>3,49,50</sup>
III. The Perceived Stress Scale (PSS) <sup>47</sup>	III. The PSS was included to provide an assessment of recent thoughts and feelings associated with stress. Perceived stress may be a dimension of distress particularly relevant to the experience of caregivers, who often take on a high task load as well as deal with the emotional sequelae of their family member's deterioration and prognosis. <sup>51</sup>
IV. The Zarit Carer Burden Scale <sup>48</sup>	IV. The Zarit Carer Burden Scale was designed to assess the perceived impact of caregiving upon emotional and psychological functioning, social life and financial functioning. <sup>48</sup> This measure has been used extensively in prior MND research <sup>52</sup> including in a study linking mindfulness to carer burden. <sup>53</sup>
<b>Quality of life</b>	
I. The Personal Wellbeing Index (PWI) <sup>54</sup>	I. The PWI is a measure of overall quality of life which assesses a person's satisfaction across eight domains of quality of life. The inclusion of a non disease-specific measure of quality of life allowed the assessment of this dimension across patients and carers. Measures of overall quality of life have also been shown in health research to provide assessment of broad life domains. <sup>56</sup>
II. The Global Life Satisfaction Item (GLS) <sup>54</sup>	II. The GLS is a measure of wellbeing administered in conjunction with the PWI which assesses a person's satisfaction with their life as a whole.
III. The Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised (ALSSQOL-R) <sup>55</sup>	III. The ALSSQOL-R provides a measure of disease-specific quality of life. The measure and has been previously utilised in randomised controlled trials of mindfulness interventions in MND, allowing us to link our findings to this earlier research.
<b>Positive psychological change</b>	
I. Benefit Finding Scale (BFS) <sup>57</sup>	I. The BFS examines a range of positive psychological cognitions or outcomes that may develop in the face of negative life events, such as the diagnosis of a life-limiting condition.
II. The Post Traumatic Growth Inventory (PTG-I) <sup>58</sup>	II. The PTG-I assesses positive outcomes reported by persons who have experienced traumatic events, including in terms of new possibilities, relating to others, personal strength, spiritual change, and appreciation of life.
<b>Mindfulness</b>	
I. Cognitive Affective Mindfulness Scale Revised (CAMS-R) <sup>59</sup>	I. The CAMS-R examines everyday mindfulness and experiences of thoughts and feelings, with higher scores representing greater levels of mindfulness.

**Table 2:** MindfulMND program content, adapted from the mindfulness-based stress reduction program

	<b>Content of the program (guided discussion and didactic material)</b>	<b>In session mindfulness practice*</b>	<b>Home practice (F=formal; I=informal)</b>
<b>Week 1:</b> Simple awareness and introduction to the body scan	<ul style="list-style-type: none"> <li>- Overview of the program, incorporating the idea of beginning a journey together and as a group</li> <li>- Overview of mindfulness research, including in MND</li> <li>- Participant introductions and warm-up activity</li> <li>- Group guidelines e.g., confidentiality</li> <li>- Mindfulness definitions and description, including in contrast with mind-wandering</li> <li>- Mindfulness as a skill requiring practice: the process of 'building the mindfulness muscle' and initial strategies to maintain motivation to practice, including identification of a 'personal vision'.</li> </ul>	<ul style="list-style-type: none"> <li>- Mindfulness of sensory experience (utilising a lavender stalk) (5 mins)</li> <li>- Body scan (10 mins)</li> <li>- Mindfulness of sound (3 mins)</li> </ul>	<p>F: Body scan (10 x 2)</p> <p>I: Mindfulness of routine activity</p>
<b>Week 2:</b> Building understanding of mindfulness, breathing practice, and dealing with stress (responding vs reacting)	<ul style="list-style-type: none"> <li>- Review of homework practice, with a focus on dealing with mind wandering ('training the puppy' metaphor).</li> <li>- Discussion of stress responses, including signs of stress (physical, cognitive and behavioural), triggers (including MND experiences) and the fight-flight response.</li> <li>- Introduction of the concept of responding versus reacting and how this relates to neurobiological processes, Introduction of the STOP practice to assist with 'slowing down' to respond rather than react.</li> <li>- Reinforcement of the importance of practice and building the mindfulness muscle, including discussion of strategies to maintain practice.</li> </ul>	<ul style="list-style-type: none"> <li>- Body scan (10 mins)</li> <li>- Mindful breathing (5 mins) – incorporating instructions for patients with MND with shortness of breath</li> <li>- Mindfulness of sound (2 mins)</li> <li>- STOP: One minute breathing space (x2)</li> </ul>	<p>F: Body scan, mindfulness of breathing, as prefer (10 x 2)</p> <p>I: Practice STOP process daily when not stressed, and also try at times of stress</p>
<b>Week 3:</b> Focus on mindfulness of breathing, working with tolerance of physical discomfort and with difficult emotions	<ul style="list-style-type: none"> <li>- Review of practice, including responding versus reacting and the use of the STOP practice</li> <li>- Dealing with physical discomfort by 'staying with it' rather than reacting (e.g., alleviating it immediately)</li> <li>- Dealing with difficult emotions- normalising of difficult emotions in MND, discussion of the function of emotions e.g., grief, worry</li> <li>- Guided discussion about two common approaches to difficult emotions including 'pushing away' versus 'getting consumed'. Introduction of the idea of mindfulness of emotions, including awareness of sensations of emotion in the body, and the metaphor of 'surfing the wave' of emotions</li> </ul>	<ul style="list-style-type: none"> <li>- Mindful breathing, incorporating instructions related to trialling 'sitting with' physical discomfort (10 mins)</li> <li>- Mindfulness of emotions practice (10 mins)</li> <li>- Safe-place exercise (10 mins)</li> </ul>	<p>F: Mindfulness of breathing, safe-space, soften-sooth-allow (15 x 2)</p> <p>I: Aware emotions (pleasant and unpleasant)</p>
<b>Week 4:</b> Maintaining mindfulness practice- how self-compassion can assist with motivation, course reflection	<ul style="list-style-type: none"> <li>- Review of practice including working with difficult emotions</li> <li>- Self-compassion- discussion of the concept and research, particularly about how self-compassion can enhance motivation (and may potentially assist with maintaining mindfulness practice)</li> <li>- Program reflections, consideration of mindfulness goals, planning of self-directed practice</li> <li>- Course evaluation</li> </ul>	<ul style="list-style-type: none"> <li>- Mindful breathing and full body awareness (10 mins)</li> <li>- Compassion meditation (10 mins)</li> <li>- Concluding mindfulness of sitting (5 mins)</li> </ul>	<p>F: Own practice, and try self-compassion</p> <p>I: Own practice, and try self-compassion 'on the go'</p>

### 3. Results

#### 3.1 PARTICIPANTS

We recruited 57 participants, of whom nine withdrew before the first session. After beginning the mindfulness program, three participants withdrew after the first session and five withdrew after the second session, yielding a program retention rate of 70%. Common reasons for withdrawing were disease progression, other health difficulties, work commitments, because their partner withdrew, and travelling for leisure.

The 40 participants who completed the program comprised 22 pwMND and 18 caregivers (Table 3). The physical function of the MND patients deteriorated across the time points as measured by the ALSFRS-R [M (SD): T1 = 36.18 (6.86), T2 = 35.14 (6.88), T3 = 34.18 (6.59), and T4 = 33.81 (6.92)].

#### 3.2 STRATIFICATION INTO HIGH AND LOW DISTRESS GROUPS

Stratification based on the M-HADS Depression subscale at T1 yielded the high distress group (n=11) and low distress group (n=28) (NB One participant - a caregiver - had missing data at T1 due to being recruited after the waitlist period). The high and low distress groups did not differ on demographic or disease-related characteristics (Table 4). When compared with the low distress group, the high distress group endorsed significantly greater demoralisation, perceived stress, and anxiety, poorer health-related quality of life (pwMND), and greater carer burden (caregivers) (Table 4). These findings supported the categorisation of participants into high and low distress groups with the M-HADS Depression subscale.

#### 3.3 IMPACT OF HIGH VS LOW DISTRESS ON ENGAGEMENT IN THE MINDFULNESS PROGRAM

All participants completed the entire group program or make-up sessions as required, with the exception of one participant in the low distress group who did not attend one session due to hospitalisation. Across the program, 10% of sessions were conducted via a 'make-up' session (specifically, there were 16 instances out of a total of 160 attendances, i.e., 40 x participants x 4 sessions, when participants who were unable to attend were provided with a supplementary session). Participants in the high distress group were more likely to require a make-up session (20% of all sessions) compared to those in the low distress group (7% of all sessions) [ $\chi^2=5.77$  (df=1)  $p<0.05$ ].

Figure 1 depicts participant engagement in formal mindfulness practice across the intervention. Participants in the high distress group demonstrated strong engagement in formal mindfulness practice in the first fortnight, with 91% practicing four or more times per week. This decreased to 72% in the second fortnight and 66% in the final fortnight. The low distress group showed

positive engagement in formal mindfulness practice in the first fortnight (77% practicing  $\geq 4$  times per week), which peaked in the second fortnight and remained high in the third fortnight (91% and 87% respectively practiced  $\geq 4$  times per week).

**Table 3:** Demographic characteristics for participants

Participant characteristics	pwMND (n = 22)	Caregivers (n = 18)
Age (M, SD)	63.6 (11.5)	61.3 (15.4)
Years formal education	15.1 (3.9)	15.2 (3.8)
Male gender (Freq, %)	18 (82)	4 (22)
History of mental health concerns	5 (23)	7 (39)
Taking psychotropic medication	2 (9.1)	3 (16.7)
Employment		
Ceased work (MND)	8 (36)	3 (17)
Retired	6 (27)	5 (28)
Full-time	3 (14)	5 (28)
Part-time or casual	4 (18)	4 (22)
Domestic duties	1 (5)	1 (6)
Current relationship		
Married	18 (82)	16 (89)
De facto	1 (5)	1 (6)
Widowed	1 (5)	--
Never married/single	1 (5)	1 (6)
Relationship-live apart	1 (5)	--
Place of birth		
Australia/New Zealand	16 (72.7)	13 (72.2)
Europe	3 (13.6)	1 (5.6)
Asia	3 (13.6)	4 (22.2)
<b>MND-related characteristics</b>		
Months since diagnosis (M, SD)	12.8 (13.3)	
Months since first MND symptom	27 (20.3)	
MND Phenotype (Freq, %)		
Lumbar	9 (40.9)	
Cervical	7 (31.8)	
Bulbar	1 (4.6)	
Flail arm	1 (4.6)	
Respiratory	2 (9.1)	
Undefined	2 (9.1)	
<b>Caregiver-related characteristics</b>		
Years known person with MND (M, SD)		36.1 (15.4)
Relationship to person with MND (Freq, %)		
Spouse/partner		15 (83.3)
Parent		3 (16.7)
Estimated hours/day spent providing care		5.1 (7.6)

**Table 4:** Comparisons of high and low distress groups at T1 on measures of psychological adjustment, demographic and disease-related variables (independent t-tests)

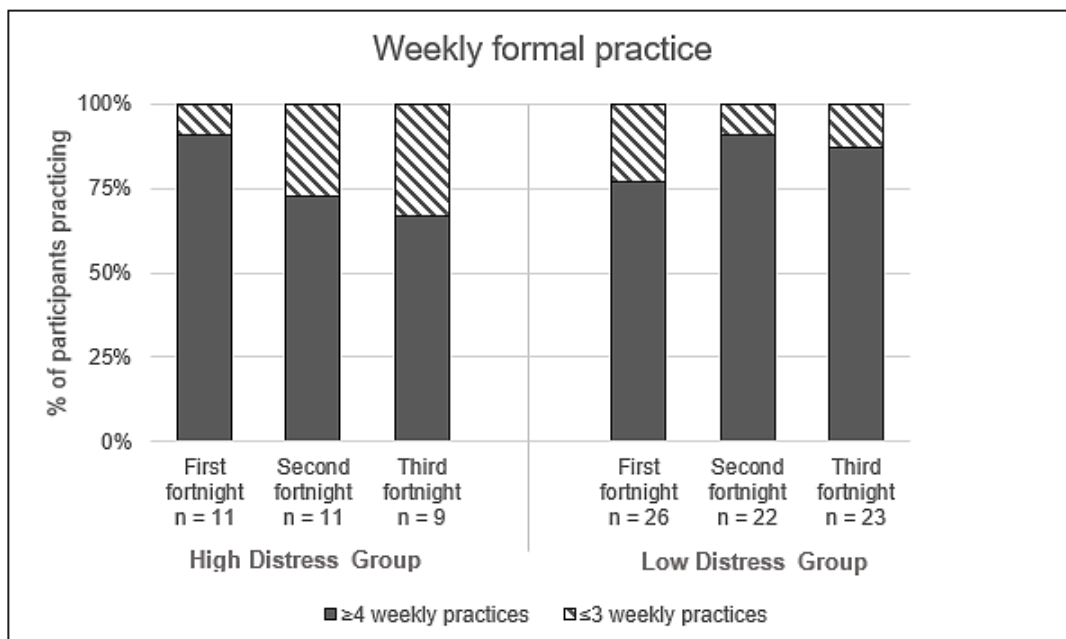
Measure	High distress (n = 11)	Low distress (n = 28)
<b>Psychological adjustment variables</b>		
	M (SD)	M (SD)
GLS	57.3 (21.5)	70.4 (18.8)
PWI	63.9 (17.0)	73.5 (13.1)
Demoralization Scale	41.6 (14.1)	22.3 (12.3)***
PSS	19.2 (5.3)	13.6 (4.5)**
M-HADS-Anxiety	8.7 (3.6)	4.5 (2.5)***
M-HADS-Depression	7.4 (1.9)	1.8 (1.6)***
CAMS	29.8 (4.8)	36.4 (6.1)**
BFS	51.3 (9.5)	54.8 (12.9)
PTGI	45.7 (12.1)	51.6 (18.1)
ALSSQOL-R <sup>a</sup>	5.2 (0.6)	7.0 (1.0)***
Zarit Carer Burden Scale <sup>b</sup>	37.2 (14.9)	16.6 (8.0)**
<b>Demographic and disease-related variables</b>		
Age	67.1 (4.35)	61.5 (15.0)
Education (years)	15.9 (3.86)	14.7 (3.7)
ALSFRS (Time 1) (pwMND)	33.2 (8.67)	37.1 (6.3)
Months since symptom onset (pwMND)	17.8 (14.52)	29.7 (21.3)
Hours spent caregiving (caregivers)	8.6 (8.60)	3.6 (7.0)
	Freq (%)	Freq (%)
Proportion of carers	6 (55)	11 (39)
Male gender	6 (55)	16 (57)
History of mental health concerns	4 (36)	8 (29)

\*\*p < .01, \*\*\*p < .001

<sup>a</sup>For pwMND, high distress n = 5, low distress n = 17

<sup>b</sup>For carers, high distress n = 6, low distress n = 11

Notes. ALSFRS = Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised, ALSSQOL-R = Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised, BFS = Benefit Finding Scale, CAMS = Cognitive Affective Mindfulness Scale, GLS=Global Life Satisfaction item, M- HADS-Anxiety = MND-adapted Hospital Anxiety and Depression Scale- Anxiety subscale, M-HADS-Depression = MND-adapted Hospital Anxiety and Depression Scale- Depression subscale, PSS = Perceived Stress Scale, PTGI= Post-Traumatic Growth Inventory, PWI = Personal Wellbeing Index, pwMND = people with MND



**Figure 1.** Weekly formal practice across the MindfulMND intervention for the high and low distress groups

### 3.4 IMPACT OF HIGH VS LOW DISTRESS ON CHANGES IN PSYCHOLOGICAL ADJUSTMENT AS A RESULT OF THE INTERVENTION

Results of the Wilcoxon signed-rank tests across the period of the waitlist and the intervention are presented in Table 5 (a: high distress group; b: low distress group). Fluctuations on the eleven measures of psychological adjustment were observed across the waitlist period. Specifically, in the high distress group, five comparisons showed small effects, three showed medium effects and one showed a large effect. In the low distress group, seven comparisons showed small effects, three showed medium effects and one showed a large effect. Based on the predominance of small and medium effects across the waitlist period, in examining effects across the intervention period, we focused on large effects only, considering these as more likely to represent changes associated with the intervention (i.e., vs. usual fluctuations).

In the high distress group, the pre-post intervention comparisons (T2-T3) showed changes with large effects on measures of psychological distress (Demoralization

Scale, Perceived Stress Scale, M-HADS Anxiety subscale), quality of life (Global Life Satisfaction item, The Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised), and positive psychological adjustment (Benefit Finding Scale). All of these indicated improved psychological functioning. Considering pre-intervention to follow-up (T2-T4) comparisons, positive psychological changes with large effects were observed on measures of psychological distress (M-HADS Anxiety subscale), quality of life (Global Life Satisfaction item) and positive psychological adjustment (Benefit Finding Scale).

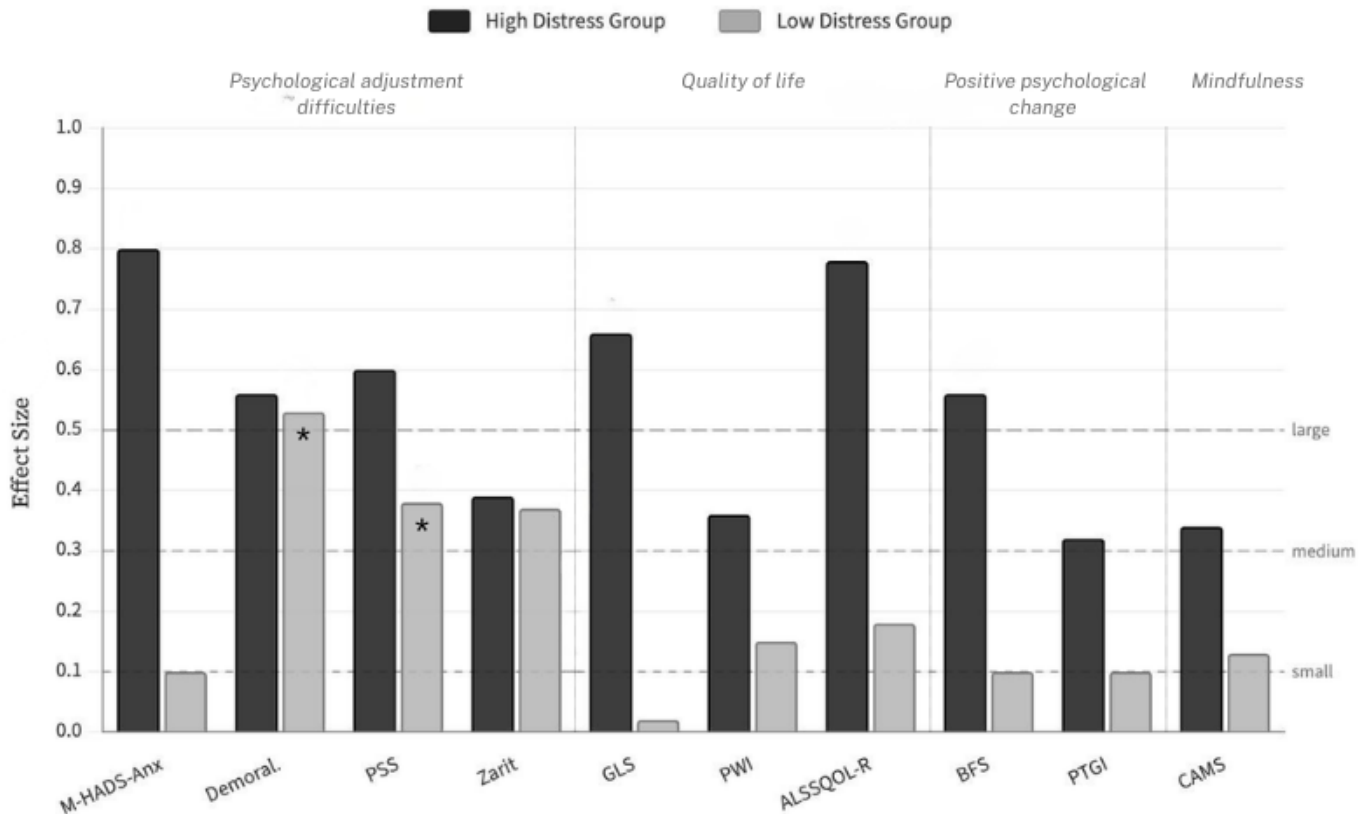
For the low distress group, Demoralization Scale scores increased from T2 to T3 (i.e., representing worse psychological adjustment) with a large effect size. This appeared to represent a return to baseline levels given that demoralisation had decreased during the waitlist period (T1 to T2). There were no other changes with a large effect size on the remaining psychological measures in the low distress group. Figure 2 illustrates the comparatively higher intervention effects for the high versus the low distress groups.

**Table 5:** Wilcoxon signed-rank tests for the waitlist, intervention and follow-up periods in the high and low distress groups

	Median				Waitlist period (T1 vs. T2)			Pre-intervention to post-intervention (T2 vs. T3)			Pre-intervention to follow-up (T2 vs. T4)		
	T1	T2	T3	T4	N	Z	Effect Size	N	Z	Effect Size	N	Z	Effect Size
<b>a) HIGH DISTRESS GROUP</b>													
M-HADS-Anxiety	10	9	8	7.5	7	0.68	0.26	9	2.4	<b>0.80*</b>	7	1.71	<b>0.65</b>
Demoralization Scale	40	36	30	32.5	10	1.23	0.39	11	1.87	<b>0.56</b>	10	1.07	0.34
PSS	19	18	17	17.5	11	0.45	0.14	10	1.89	<b>0.60</b>	9	0.78	0.26
Zarit Carer Burden Scale	39.5	38	36.5	39	5	0.41	0.18	6	0.95	0.39	5	0.81	0.36
GLS	60	50	60	75	8	1.29	0.46	9	1.98	<b>0.66*</b>	9	2.27	<b>0.76*</b>
PWI	60	58.8	71.3	63.8	11	0.62	0.19	11	1.21	0.36	9	1.31	0.44
ALSSQOL-R	5.3	5.5	6.3	5.4	5	0.94	0.42	5	1.75	<b>0.78</b>	5	0.41	0.18
BFS	53	53	56	60.5	10	0	0.00	9	1.67	<b>0.56</b>	10	1.84	<b>0.58</b>
PTGI	41	42	54	47	10	0.26	0.08	10	1.02	0.32	9	1.07	0.36
CAMS	29	31	31	34	11	2.1	<b>0.63*</b>	10	1.08	0.34	9	1.37	0.46
<b>b) LOW DISTRESS GROUP</b>													
M-HADS-Anxiety	4	5	4	4	20	0.82	0.18	19	0.45	0.10	18	0.66	0.16
Demoralization Scale	20.5	17.5	21	22	23	2.51	<b>0.52*</b>	24	2.58	<b>0.53*</b>	25	1.88	0.38
PSS	13.5	12.5	14	11	26	1.9	0.37	27	1.99	0.38*	23	0.11	0.02
Zarit Carer Burden Scale	15	17	15	14.5	10	0.56	0.18	10	1.17	0.37	9	0.53	0.18
GLS	80	80	80	80	18	1.29	0.30	20	0.08	0.02	16	0.86	0.22
PWI	76.3	76.3	76.3	75.6	27	1.68	0.32	20	0.67	0.15	22	1.87	0.40
ALSSQOL-R	7.1	7	6.8	6.6	17	0.69	0.17	13	1.58	0.44	16	1.29	0.32
BFS	55.5	59	60	62.5	27	1.18	0.23	25	0.9	0.18	23	1.31	0.27
PTGI	52	54	57	57.5	28	1.09	0.21	24	0.47	0.10	25	0.92	0.18
CAMS	38	37	36	35	24	0.78	0.16	21	0.61	0.13	21	0.54	0.12

\*p < .05

Notes. Effect sizes: 0.1 = small, 0.3 = medium, and 0.5 = large (marked in bold). N= the number of ranks, excluding ties. ALSSQOL-R = Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised, BFS = Benefit Finding Scale, CAMS = Cognitive Affective Mindfulness Scale, GLS = Global Life Satisfaction item, M- HADS-Anxiety = MND-adapted Hospital Anxiety and Depression Scale- Anxiety subscale, M-HADS-Depression = MND-adapted Hospital Anxiety and Depression Scale- Depression subscale, PSS = Perceived Stress Scale, PTGI= Post-Traumatic Growth Inventory, PWI = Personal Wellbeing Index. For measures of psychological adjustment (M-HADS, PSS, Demoralization Scale, and Zarit Carer Burden Scale), higher scores represent poorer psychological functioning. For measures of quality of life (GLS, PWI, ALSSQOL-R), higher scores represent better quality of life. For measures of positive psychological change (BFS, PTGI), higher scores represent positive psychological adjustment. For the measure of mindfulness (CAMS), higher scores represent greater levels of mindfulness.



**Figure 2:** Pre- to post- intervention effect sizes derived from Wilcoxon signed rank tests, by high and low distress groups. All medium (>0.3) and large (>0.5) effect size changes represent improvements in psychological adjustment difficulties, quality of life, positive psychological change and mindfulness, apart from those identified with an asterisk (\*). ALSSQOL-R = Amyotrophic Lateral Sclerosis Specific Quality of Life-Revised, BFS = Benefit Finding Scale, CAMS = Cognitive Affective Mindfulness Scale, Demoral. = Demoralisation Scale, GLS = Global Life Satisfaction item, M- HADS-Anx = MND-adapted Hospital Anxiety and Depression Scale- Anxiety subscale, PSS = Perceived Stress Scale, PTGI= Post-Traumatic Growth Inventory, PWI = Personal Wellbeing Index, Zarit = Zarit Carer Burden Scale.

## 4. Discussion

To inform future service delivery, we set out to understand the differential effects of learning mindfulness for people affected by MND who varied in their levels of baseline distress. The high distress group (28% of participants) showed poorer baseline psychological adjustment on a range of measures, as compared to the low distress group (72%). The high distress group showed excellent engagement in the MindfulMND program (attendance and completion of mindfulness practice), and demonstrated post-program psychological improvements on multiple psychological adjustment measures (anxiety, depression, demoralisation, perceived stress, quality of life, health-related quality of life and benefit finding). The low distress group also showed excellent engagement in the program but no change on psychological adjustment measures.

### 4.1 THE IMPACT OF DISTRESS LEVELS ON ENGAGEMENT WITH THE INTERVENTION

The overall high retention and attendance rates further support the acceptability of mindfulness interventions for people with neurological disorders such as MND,<sup>23,60</sup> regardless of levels of distress. Previous research has highlighted the importance of flexibility for people with neurological disorders such as MND.<sup>41,61</sup> The high distress group made more use of make-up sessions than the low distress group, possibly reflecting greater feelings of overwhelm for these participants, and therefore the need

to reduce practical commitments to alleviate pressure. Flexible arrangements may be particularly important for those who are feeling emotionally stretched.

The overall high levels of between-session practice were consistent with other mindfulness research<sup>60</sup> and provided further evidence of positive engagement in the MindfulMND program. This is despite somewhat different patterns of practice over time in the high and low distress groups. In the high distress group, completion of between-session formal practice was initially extremely high (91% practicing  $\geq 4$  times a week), with this intensity somewhat dropping off as the program progressed (66% practicing  $\geq 4$  times a week in the final fortnight). Early distress may have motivated the initial burst of practice. This may have then been difficult to maintain, however, possibly due to depressive symptoms such as lowered motivation and negative ruminations, which may have impeded mindfulness practice.<sup>62,63</sup> In contrast, excellent engagement in formal mindfulness practice in the low distress group was sustained (more than 75% practiced 4+ times weekly across the program), suggesting that participants may have been enjoying and experiencing benefits from continued practice.

### 4.2 THE IMPACT OF DISTRESS LEVELS ON INTERVENTION EFFICACY

The finding that learning mindfulness led to improved psychological adjustment for those with high distress but

not those with low distress is consistent with studies in the oncology literature and a recent study of early-onset MND, which have shown greater post psychological intervention improvements for those with higher baseline distress.<sup>27,28,64,65</sup> While previously conducted randomised controlled trials of mindfulness in MND have shown positive intervention effects for anxiety, depression and quality of life,<sup>18,20</sup> our study shows that averaging across participants can mask individual variation in responses to interventions. It supports the notion that it is necessary to consider the presence of heterogenous subgroups when examining efficacy outcomes.<sup>17</sup>

We incorporated a broader range of measures than has been included in prior mindfulness research in MND, which to date has largely focused on mood (depression and anxiety) and health-related quality of life,<sup>18,20,28</sup> by also including measures of demoralisation, stress, general quality of life, mindfulness and positive psychological change (benefit-finding and post-traumatic growth). The finding of increased benefit finding in the high distress group is particularly significant given the knowledge of the deteriorating course of MND and the life-limiting prognosis. There were also changes in post-traumatic growth in a positive direction (medium effect sizes). These findings add to widespread reports of growth following a crisis<sup>58,66-70</sup> and highlight a possible role for mindfulness in facilitating positive psychological change.<sup>69</sup> It also highlights the need to include consideration of a range of psychological adjustment outcome measures- beyond measures of distress- to fully characterise psychological adjustment.<sup>16,29,67</sup>

Despite the inclusion of eudemonic in addition to hedonic measures of psychological adjustment, no changes in the low distress group were detected. Measures which focused on positive psychological growth could be subject to ceiling effects as measures of psychological distress are subject to floor effects,<sup>27</sup> however it is also possible that no change took place. Post-traumatic growth theory has proposed that a decrement in psychological adjustment necessarily precedes a process of grappling cognitively with the meaning of aversive experience, thus allowing positive psychological growth.<sup>70</sup> Those with lower levels of baseline psychological distress may have been less likely to engage in this cognitive process of meaning making, including in the presence of a mindfulness intervention. Despite the absence of detectable change in the low distress group, the low distress participants clearly continued to engage in practice through the program, implying that this was felt to be valuable. Perceived benefit from the program was also supported by group discussion with participants and globally positive responses to the anonymous satisfaction survey.

#### 4.3 STUDY LIMITATIONS AND FUTURE DIRECTION

In line with population-based studies,<sup>71</sup> a higher proportion of pwMND (82%) were males. Since caregivers were predominantly spouses, with only three being adult children, there was a correspondingly high proportion of females as caregivers (78%). Our results may therefore not be representative of dyads of women with MND/male caregivers, non-spouse carers and same sex couples. The MND phenotypes observed in our study comprised a relatively high proportion of lumbar and

cervical onset MND, likely due to the 100% intelligibility inclusion criteria which may have prohibited some participants with bulbar onset MND from participating. This also restricted the generalisability of the results, particularly as bulbar onset MND has been linked to increased psychological adjustment difficulties compared with other phenotypes.<sup>72-74</sup>

Despite the excellent engagement of participants once they agreed to participate, the initial recruitment into our study was challenging, as has been reported in a number of other studies of psychological interventions in MND.<sup>18,75</sup> This resulted in a smaller sample size than our planned 60-80 participants. Reasons for not participating provided by participants included the time involved, restrictions to functioning due to MND symptoms, pre-existing requirements of MND-related research and clinical activities, limited interest, patient concerns about burdening their caregiver and feeling emotionally overwhelmed.<sup>76</sup> At a time of reduced time and energy resources, patients with MND and their caregivers may prioritise other valued activities (e.g., spending time with family) over participating in a program which teaches a new (albeit potentially useful) skill. This underscores the importance of tailoring interventions to be as accessible and feasible as possible.<sup>41</sup>

The small sample size prohibited separation of the data into patient and carer groups for analysis. Given our study's primary interest in the role of baseline distress on intervention outcomes, we chose to combine the patient and carer groups so we retained adequate statistical power to perform the required analyses. Patients and carers are impacted by MND in ways that are both similar, such as the experience of progressive loss and fears of the future, and different, such as the personal impact on mortality and loss of independence for pwMND but not caregivers, versus the increase in domestic and caring tasks for caregivers. It is quite possible that there are differences in patient and carer psychological outcomes after learning mindfulness, which could not be discriminated due to combining results. In addition, there were some pwMND who attended with a caregiver while others attended alone. Attending as a dyad may provide benefits such as reinforcing mindfulness practice and developing shared coping strategies,<sup>77</sup> although for some it may inhibit fully discussing feelings and concerns.<sup>41</sup>

Another challenge that arose during the recruitment and delivery of the mindfulness intervention was the COVID-19 pandemic and associated lockdowns. Exploratory analysis showed no difference in intervention effects based on the mode of program delivery (face-to-face, online, or combination), consistent with the findings of Korupolu and colleagues,<sup>60</sup> however some effect cannot be excluded. Although the shift from a face-to-face to an online platform resulting from the COVID pandemic can be considered as a disadvantage from a research perspective, from a clinical perspective this shift forced our program to transition to a mode of delivery that is more accessible and realistic for MND patients and their caregivers. This has been a change which we have retained in running multiple subsequent MindfulMND programs.

## 5. Conclusion

Access to specialised psychological interventions for those affected by MND is typically limited, with the number of patients seeking a service outweighing the capacity to respond.<sup>78,79</sup> The results suggest that where resources are stretched, targeting mindfulness programs towards MND patients and carers with higher levels of distress may yield the greatest measurable clinical benefit. Screening for psychological distress has become routine in other illness groups (e.g., in the oncology field), with tiered models suggesting psychological intervention responses appropriate to different levels of distress.<sup>80,81</sup> Screening tools such as the M-HADS may assist in the allocation of psychological services to those affected by MND who are most likely to experience measurable benefit. To support engagement with mindfulness practices and manage the impact of negative ruminations, patients with high distress levels may benefit from consideration of how to best structure their practice (e.g., shorter but more frequent focused practices), and may also benefit particularly from practices to assist difficult emotions, such as those which support the identification and processing of emotions such as grief (e.g., mindfulness of emotions practice), and those which support patients to find distance from difficult emotions (e.g., safe place practice). These kind of approaches may enhance the already apparent benefits of learning mindfulness for those with higher distress.

Since we conducted this research, we have focused on recruiting patients and carers with higher levels of distress, and have continued to focus on strategies to reduce barriers to attendance in the MindfulMND program, including further reducing the session number (3) and duration (90 minutes) and as mentioned, focusing on online participation with the flexibility of 'make-up' sessions. Even with this abbreviated program, participants have

anecdotally reported excellent benefit. Further work is needed to examine the minimal dose and frequency of home practice required to initiate and maintain psychological changes,<sup>60</sup> to adapt the program for those with bulbar-related communication difficulties, and to examine the differences between participant experience of and outcomes related to online versus face-to-face mindfulness interventions. Ideally, future investigations would encompass longer follow-up periods and an active control group. Such research may assist with optimising the accessibility and efficacy of psychological interventions for those with a forshortened sense of time on the rocky and deteriorating illness trajectory of MND.

## 6. Conflicts of Interest Statement

The authors have no conflicts of interest to declare.

## 7. Funding Statement

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