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ORIGINAL RESEARCH

Experiences of acceptance and commitment therapy for people living with motor neuron disease (MND): a qualitative study from the perspective of people living with MND and therapists

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Abstract

Background: Motor neuron disease (MND) is a progressive, fatal, neurodegenerative condition that affects motor neurons in the brain and spinal cord, resulting in loss of the ability to move, speak, swallow and breathe. Acceptance and commitment therapy (ACT) is an acceptance-based behavioural therapy that may be particularly beneficial for people living with MND (plwMND). This qualitative study aimed to explore plwMND's experiences of receiving adapted ACT, tailored to their specific needs, and therapists' experiences of delivering it.

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Method: Semi-structured qualitative interviews were conducted with plwMND who had received up to eight 1:1 sessions of adapted ACT and therapists who had delivered it within an uncontrolled feasibility study. Interviews explored experiences of ACT and how it could be optimised for plwMND. Interviews were audio recorded, transcribed and analysed using framework analysis.

Results: Participants were 14 plwMND and 11 therapists. Data were coded into four over-arching themes: (i) an appropriate tool to navigate the disease course; (ii) the value of therapy outweighing the challenges; (iii) relevance to the individual; and (iv) involving others. These themes highlighted that ACT was perceived to be acceptable by plwMND and therapists, and many participants reported or anticipated beneficial outcomes in the future, despite some therapeutic challenges. They also highlighted how individual factors can influence experiences of ACT, and the potential benefit of involving others in therapy.

Conclusions: Qualitative data supported the acceptability of ACT for plwMND. Future research and clinical practice should address expectations and personal relevance of ACT to optimise its delivery to plwMND.

Key learning aims

(1) To understand the views of people living with motor neuron disease (plwMND) and therapists on acceptance and commitment therapy (ACT) for people living with this condition.
(2) To understand the facilitators of and barriers to ACT for plwMND.
(3) To learn whether ACT that has been tailored to meet the specific needs of plwMND needs to be further adapted to potentially increase its acceptability to this population.

Keywords: acceptability; acceptance and commitment therapy; motor neuron disease; qualitative

Introduction

Motor neuron disease (MND) is a progressive neurological condition in which degeneration of motor neurons in the spinal cord and motor cortex causes muscle wasting, stiffness and weakness. It affects approximately 2–3 people in every 100,000 (Hardiman *et al.*, 2017), and life expectancy is typically 2–4 years following diagnosis (Goutman *et al.*, 2022). There is no cure for MND, and riluzole, the only disease-modifying treatment licensed in the UK, has limited efficacy (Miller *et al.*, 2012). Consequently, current treatments focus on symptomatic relief and reducing the negative impact of the disease on quality of life.

Psychological distress, including depression and anxiety, is common in people living with MND (plwMND). For example, a recent systematic review reported a pooled prevalence rate of 34% for depression, with rates varying depending on the assessment tool used (Heidari *et al.*, 2021). Similarly, prevalence rates of up to 30% have been reported for anxiety (Kurt *et al.*, 2007). Psychological distress in plwMND is associated with numerous factors, including poorer quality of life (Edge *et al.*, 2020; van Groenestijn *et al.*, 2016), increased hopelessness (Paganoni *et al.*, 2017) and increased risk of suicide (Fang *et al.*, 2008). Substantial levels of psychological distress and burden have also been reported in caregivers of plwMND due to the nature of MND and the challenges it brings (Aoun *et al.*, 2013). Despite calls to address psychological distress in both MND healthcare and as a focus of research (Harris *et al.*, 2018; Pagnini and Simmons, 2018), evidence-based guidance on specific psychotherapeutic interventions for plwMND is limited due to a paucity of high-quality research studies (Gould *et al.*, 2015; Oh *et al.*, 2024; Simpson *et al.*, 2021; Zarotti *et al.*, 2021).

One form of psychological therapy that offers potential promise for managing psychological distress and quality of life in plwMND is acceptance and commitment therapy (ACT) (Hayes *et al.*, 2012). ACT encourages the development of psychological flexibility through a combination of acceptance and mindfulness-based strategies in conjunction with motivation and behavioural change strategies. Its focus on engagement in values-based living, alongside whatever negative thoughts, emotions and physical sensations are experienced, distinguishes it from conventional cognitive behavioural therapy (CBT) where the focus is more on alleviating distress or symptoms. This alternative focus means that it may be a particularly suitable approach for those with chronic or life-limiting conditions.

In line with this, ACT has an established evidence base in a range of mental and physical health conditions, including chronic pain, depression, anxiety, substance use and transdiagnostic groups (Gloster *et al*., 2020). In contrast, evidence of its effectiveness in neuromuscular and neurological disorders is limited, but growing (Graham *et al*., 2016). For example, statistically significant improvements in quality of life, depression and anxiety at 9 weeks follow-up were reported in a randomised controlled trial (RCT) of ACT plus usual care for chronic muscle diseases in comparison with usual care alone (Rose *et al*., 2023). Similarly, significant improvements in psychological quality of life were reported in a small pilot RCT of ACT for people living with Parkinson's disease in comparison with treatment-as-usual (Ghielen *et al*., 2017). Additionally, improvements in psychological distress, trait mindfulness, values-based living and psychological flexibility have been reported in a service evaluation of ACT groups for people living with neurological conditions (Bowers *et al*., 2021).

With respect to the potential acceptability of ACT for plwMND, a series of recommendations have previously been made with respect to how psychological interventions can be adapted for the specific psychological, physical, cognitive and communication needs of this population (Weeks *et al*., 2019). These recommendations were based on feedback from a series of qualitative interviews with plwMND, caregivers and healthcare professionals. They were used to develop an ACT intervention, tailored to the needs of plwMND, which was subsequently evaluated within an uncontrolled feasibility study (Gould *et al*., 2023). ACT appeared to be both feasible to deliver and acceptable to plwMND, as indicated by high session attendance and satisfaction rates. Furthermore, possible signals of efficacy were found with respect to small improvements in anxiety and psychological quality of life from baseline to 6-month follow-up. The clinical effectiveness of ACT adapted for plwMND was confirmed in a recent RCT (Gould *et al*., 2024). This reported between-group differences in favour of ACT plus usual care *vs* usual care alone for quality of life and depression at 6 and 9 months post-randomisation, psychological inflexibility at 9 months and brief health status at 6 months. Again, high session attendance and satisfaction rates suggested the intervention was acceptable to plwMND. However, uncertainty remains regarding plwMND's qualitative experiences of ACT given the quantitative focus of the RCT.

As part of the earlier uncontrolled feasibility study (Gould *et al*., 2023), qualitative interviews with plwMND who had received the intervention and therapists who had delivered it were conducted to further assess the acceptability of ACT for plwMND. These interviews aimed to explore: (i) the acceptability of ACT for plwMND (including barriers to and facilitators of engagement in and delivery of ACT); (ii) perceived benefits from receiving ACT; and (iii) how ACT could be refined in order to increase its acceptability to this population. Qualitative findings from the perspective of plwMND who had received the intervention and therapists who had delivered it are reported here. To the authors' knowledge, this is the first study to qualitatively report on the acceptability of ACT for plwMND.

Method

This study reports on qualitative data from a pre-registered, uncontrolled study that examined the feasibility and acceptability of ACT adapted for plwMND (ISRCTN Registry: ISRCTN12655391). The Standards for Reporting Qualitative Research checklist (O'Brien *et al*., 2014) and the template for intervention description and replication (TIDieR) checklist (Hoffmann *et al.*, 2014) are provided in Supplementary material (Files 1–2) to support transparent reporting.

Design

Grounded in critical realism, we sought to understand participants' perspectives of their experiences (Willis, 2007). Here we recognise symptoms of MND and components of ACT as existing in an independent reality, but focus on understanding how plwMND and therapists experience and make sense of that reality in the context of their lives.

Participants in qualitative interviews

PlwMND were aged 18 years and over, and had a diagnosis of definite, laboratory-supported probable or probable familial or sporadic ALS (which is diagnostically synonymous with MND; Al-Chalabi *et al.*, 2016) using the World Federation of Neurology's El Escorial criteria (Brooks *et al.*, 2000). PlwMND were excluded if they: (i) were lacking capacity to provide fully informed consent (either written, verbally or via the use of a communication aid); (ii) had insufficient understanding of English to enable engagement in ACT or complete questionnaires; (iii) had a clinical diagnosis of dementia; (iv) required gastrostomy feeding or non-invasive ventilation (i.e. were at stage 4 of King's clinical staging; Roche *et al.*, 2012); (v) were currently receiving psychological therapy or were unwilling to refrain from psychological therapy during the receipt of ACT; (vi) required treatment for severe psychiatric disorder or were expressing suicidal ideation with active plans/suicidal behaviours and intent; or (vii) had other medical factors that could compromise full study participation.

Therapists were clinical psychologists, counselling psychologists or psychotherapists with training in cognitive behavioural therapy, with a minimum of one year's experience of delivering psychotherapy interventions.

Recruitment

Recruitment of plwMND to the uncontrolled feasibility study is described in Gould *et al.* (2023). Recruitment of plwMND and therapists to this qualitative study via convenience sampling was as follows. With the exception of those who withdrew from the feasibility study and so could not be invited to participate in interviews, plwMND who participated in the feasibility study were approached by local site staff or therapists and invited to participate in qualitative interviews. Those who gave consent for contact were then approached by one of two researchers (K.W. or C.R.) via telephone or email. Therapists who delivered ACT within the feasibility study were also invited to participate and were approached by K.W. or C.R. All participants provided fully informed written consent to participate or verbal consent/consent via the use of a communication aid, verified by an independent witness, for those who could not provide written consent.

Intervention

PlwMND received up to eight sessions of ACT that had been tailored to the specific physical, communication, cognitive and psychological needs of plwMND in accordance with previous qualitative findings (Weeks *et al.*, 2019). A brief summary of how ACT was adapted for the needs of plwMND is listed in Table 1. Sessions were delivered on a one-to-one basis, for up to one hour each, in the clinic/home or via video call, and were supplemented by audio recordings of ACT exercises. Sessions were mostly weekly, extending to fortnightly and then monthly for the last two sessions to facilitate a graded ending. An outline of each of the sessions is provided in Table 2. With the consent of the person with MND, caregivers were invited to attend the assessment

Table 1. A brief summary of how ACT was adapted for plwMND

Domain	Adaptation
Core ACT processes	Early focus on values in sessions encouraged (where appropriate) as this may improve outcomes and engagement in older people (Petkus and Wetherell, 2013; Wetherell *et al*., 2011) and MND commonly affects those in their 60s and older Present moment awareness exercise included at the start of each session as this may help plwMND manage periods when they can no longer move (Pagnini *et al*., 2014) A range of exercises and metaphors included to foster defusion and perspective taking in relation to MND as it is important to help plwMND adopt a more flexible perspective in relation to the condition (Pagnini *et al*., 2015) Selection, optimisation and compensation principles (Baltes and Baltes, 1990) incorporated into exercises focused on committed action to help overcome external barriers associated with MND
Therapeutic delivery	Flexibility in session delivery offered with respect to geographical location, pace, content, length, number and timing of the sessions ACT terminology adapted to suit the individual by establishing people's preferred terms for concepts (such as willingness rather than acceptance or home practice rather than homework) Emphasis on choice through incorporation of the willingness question throughout sessions as giving plwMND opportunities to exert control and make decisions about their healthcare and treatment can have a positive impact on their well-being (King *et al*., 2009) plwMND given the opportunity and space to discuss existential and end of life issues within an ACT-consistent approach as this can help to normalise end of life conversations and help plwMND establish a sense of control over the process (Ray *et al*., 2012) With consent from the person with MND, involvement of caregivers in the first session (to communicate the aims of ACT) and in sessions focused on committed action (to aid goal planning and problem solving with respect to potential external barriers) Online client and therapist peer support forums established to provide opportunities to receive additional support from others
Communication difficulties	A range of strategies adopted (e.g. checking individual preferences with respect to preferences for communication and seating position of the speaker, maintaining eye contact with the person with MND and not the communication device, working at a slower pace, etc) Amount of material covered in a session modified by the therapist, depending on the speed of communication and pace of the session Verbal ACT exercises replaced with non-verbal ACT exercises
Physical difficulties	Mobility issues: written ACT exercises replaced with verbal or non-verbal ACT exercises, ACT exercises adapted to reduce need for physical movement, adapted use of physical props in ACT exercises, etc. Breathing issues: alternatives to focusing on the breath provided in present moment awareness exercises Fatigue issues: shorter sessions and/or breaks provided in sessions
Mild cognitive and behavioural difficulties	Concrete rather than abstract ACT metaphors and experiential exercises used Visual and/or physical props or physical demonstrations used to facilitate delivery of ACT metaphors and experiential exercises Generic strategies adopted for addressing cognitive changes and/or behavioural changes in MND

ACT, acceptance and commitment therapy, MND, motor neuron disease; plwMND, people living with MND.

session and sessions examining committed action. Usual multi-disciplinary care was provided in addition to ACT.

All sessions, apart from the first and last, adopted the following structure: (i) present moment awareness exercise; (ii) brief ratings of open, aware and engaged processes; (iii) assessment of suicidal ideation; (iv) discussion of the previous session and home practice; (v) introduction to a key ACT process, together with associated experiential exercises and metaphors and home practice tasks (see Table 2); and (vi) session summary and home practice task. Although each

Table 2. An outline of each of the sessions of the ACT intervention tailored for plwMND, together with accompanying ACT exercises and metaphors

Session	Main focus[a]	Content	ACT exercises and metaphors[b]
1	Assessment	Assessment of current issues, discussion of aims of therapy and introduction to ACT	Introducing ACT Online supplemental material: Introducing ACT
2–7[c]	Values	Clarifying what is important and matters to them and the type of person they want to be alongside MND	Lifetime achievement award, Values list, Values questions or Life compass Online supplemental material: Small steps exercise
	Acceptance/ willingness	Exploring willingness to have difficult thoughts, emotions and physical sensations in order that they can do what they want to do or be the type of person they want to be alongside MND	Passengers on the bus, Accepting all of you or Physicalising exercise Online supplemental material: Willingness exercise
	Defusion and contact with the present moment	Exploring ways of 'unhooking' or 'stepping back' from difficult thoughts, emotions and physical sensations that are getting in the way of them doing what they want to do or being the type of person they want to be alongside MND, and exploring ways of being in the present moment rather than worrying about the future or dwelling on the past	'I notice I'm having the thought . . . ', Singing or saying a thought, Writing a thought, 'Milk, milk, milk' or Imagine a thought on a computer screen and Notice 5 things or Tracking your thoughts in time Online supplemental material: Leaves on a stream
	Self-as-context	Exploring ways of looking at their thoughts, emotions and physical sensations from a different viewpoint – seeing themselves as separate from their thoughts, emotions and physical sensations	Labels exercise, House and furniture metaphor or Very brief self-as-observer Online supplemental material: Connecting with the noticing you
	Committed action 1	Exploring ways of overcoming external barriers using principles of selection, optimisation and compensation	Willingness and action plan Online supplemental material: Your kind friend
	Committed action 2	Setting goals and actions that move them towards doing what they want to do or being the type of person they want to be alongside MND	Willingness and action plan Online supplemental material: Problem solving for external problems
8	Review	Review of key concepts and skills explored in the sessions and how they can carry on applying these in their daily lives	Online supplemental material: Hexaflexercise

[a] Although each session broadly focused on a specific ACT process, therapists were encouraged to bring other ACT processes into each session.

[b] Brief descriptions of the ACT exercises are provided in the Supplementary material: File 5. Therapists chose which and how many ACT exercises to deliver in each session, dependent on the person's needs and preferences.

[c] The order in which ACT processes were focused on was chosen by the therapist, according to each person's individualised ACT case conceptualisation. Each session, apart from the first, started with the centring exercise, and each session explored small steps that could be taken in service of the person's values.

session broadly focused on a specific ACT process, therapists were encouraged to bring other ACT processes into each session. The order in which ACT processes were focused on was chosen by the therapist, according to each person's individualised ACT case conceptualisation. Therapists could modify the pace of the session, as necessary, and were provided with a choice of a range of metaphors and exercises that could be delivered in each session to suit individual needs and preferences. Intervention delivery was supported by the use of a therapist manual detailing session outlines, metaphors and experiential exercises, together with a client workbook, which could be used flexibly in order to address individual ACT case conceptualisations, needs and preferences.

Qualified clinical psychologists, counselling psychologists and CBT therapists, who had been delivering psychotherapy interventions for a minimum of one year post-qualification, were involved in intervention delivery. All study therapists completed a 4-day training course in ACT for plwMND prior to delivering the intervention (irrespective of previous training or experience). Training included: (i) information about MND, common psychological issues in MND, and working with plwMND; (ii) the ACT model, metaphors and experiential exercises that address each of the ACT core processes, ACT assessment and case conceptualisation, and flexibly application of ACT core processes; and (iii) how to adapt ACT for plwMND. Therapists were offered weekly group supervision via telephone by two clinical psychologists and a psychiatrist with five or more years of experience of ACT. Therapists were encouraged to attend these sessions on at least a fortnightly basis. All therapy sessions were audio recorded using encrypted digital voice recorders. Ten per cent of sessions were randomly chosen to be assessed for treatment fidelity using the ACT Treatment Integrity Coding Manual (Plumb and Vilardaga, 2010) by two independent ACT therapists. Further details about the intervention and assessment of treatment fidelity are available in Gould *et al.* (2023).

Data collection

Semi-structured interviews with 14 plwMND were conducted via telephone ($n = 12$), videoconference ($n = 1$) or written questionnaire ($n = 1$), according to participants' preferences. Interviews with 11 therapists were conducted via telephone. The number of plwMND and therapists who did not participate in interviews is shown in Fig. 1, along with reasons for this. These sample sizes are supported by previous research suggesting that data saturation occurs within 12 interviews, with new themes in qualitative data emerging infrequently thereafter (Guest *et al.*, 2006). Interviews were conducted by two research assistants: the majority ($n = 21$) were conducted by C.R., with three being conducted by K.W. Participants were reminded that the interviews were confidential and that the aim was to elicit a full range of opinions, including any negative experiences or feedback.

Initial topic guides were discussed with the Patient and Public Involvement Groups and the Trial Management Group and revised according to their recommendations (see Supplementary material: File 3). Topic guides with prompts were then used flexibly to ensure consistency, support participants in communicating priorities and concerns and allow for the introduction of participant-driven topics (see Supplementary material: File 3). Topics explored were: (i) the acceptability of ACT for plwMND (including barriers to and facilitators of engagement in and delivery of ACT); (ii) perceived changes as a result of receiving ACT; and (iii) recommended changes to the ACT intervention in order to increase its acceptability to this population. Field notes were made during interviews. Interviews with plwMND lasted an average of 33.7 minutes ($SD = 10.7$), while interviews with therapists lasted, on average, 50.4 minutes ($SD = 9.2$). Participants were given the option to split interviews into multiple sessions and invite another friend or family member to attend with them, if preferred. They were also offered breaks to manage fatigue during the interviews, which were conducted at a pace set by the person with MND. All verbal interviews were audio recorded, transcribed verbatim using a third-party transcription service, and checked for accuracy and anonymised by C.R. or K.W.

Data analysis

C.R. independently reviewed all interviews and V.F. independently reviewed seven of them, and through discussion, developed an initial thematic framework (Gale *et al.*, 2013; Ritchie *et al.*, 2014) around *a priori* themes, such as the acceptability of ACT for plwMND, which also included emergent themes and subthemes from the data. C.R. subsequently applied this framework, indexing instances of themes, across all interviews. NVivo 12 was used to manage data and conduct thematic analyses using the Framework Method (Gale *et al.*, 2013). This approach was chosen for two reasons: (i) due to the applied focus on questions of acceptability and feasibility; and (ii) as this approach facilitates comparison of patients' and therapists' perspectives. C.R. then

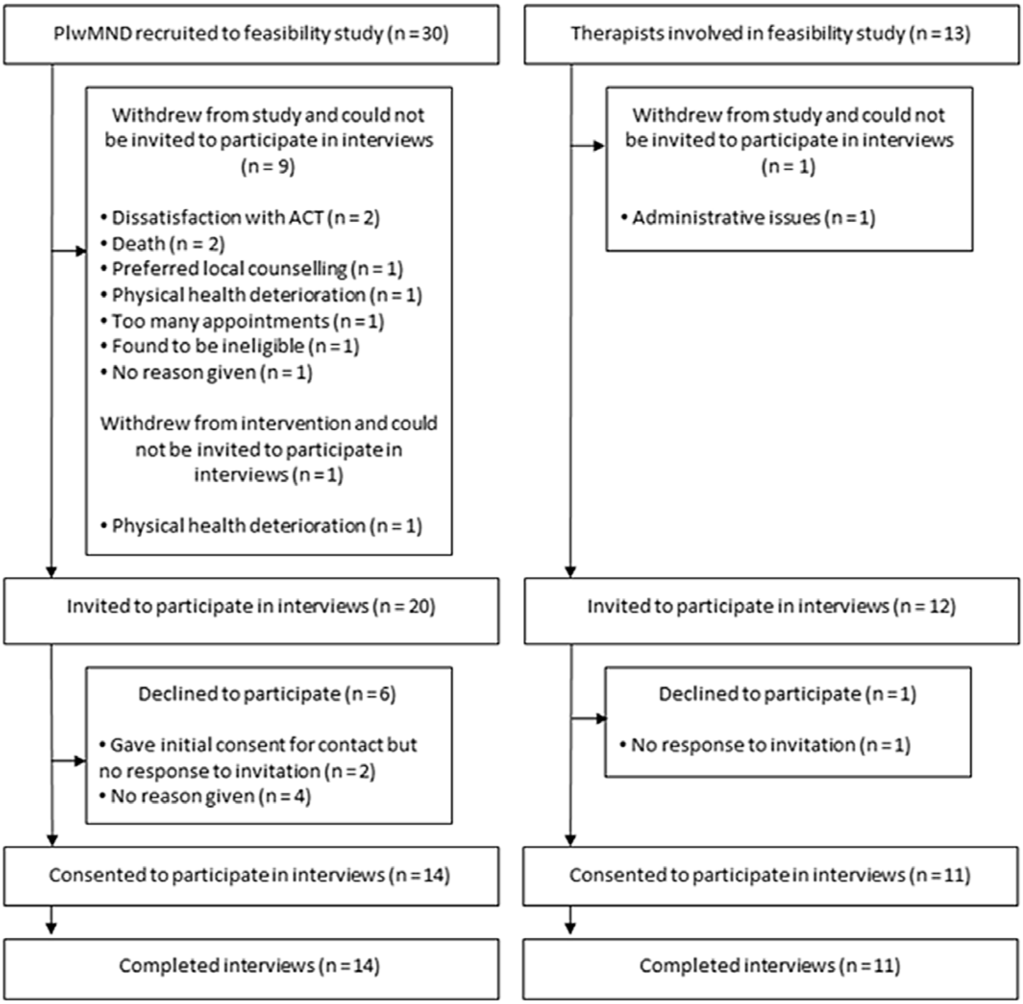

Figure 1. Recruitment flow of participants.

reviewed the range and diversity of data extracts within each theme and subtheme. At this stage, data from the interviews with plwMND and therapists were compared and contrasted, moving from surface meanings of the data to more analytic properties, to unite the thematic framework. The process of interpretation was supervised by V.L., who reviewed all coding and theme descriptions, and R.G., who reviewed theme descriptions. Further details about the analysis process are outlined in the Supplementary material (File 6).

Trustworthiness

Multiple methods were used to enhance the trustworthiness of the findings. These included keeping field notes to help contextualise and interpret the data and using the topic guide flexibly to follow participants' concerns. Multiple coding and supervision meetings were used to support reflexivity and help identify and examine alternative interpretations of the data. Additionally, the thematic framework was sense checked at multiple stages of the analysis with our Patient and Caregiver Advisory Group, who had lived experience of living with or being affected by MND.

Reflexive statement

Our interpretivist approach acknowledges that researcher influence inevitably shapes the processes of knowledge production. The interviewers (C.R. and K.W.) were white British females. Both had an MSc, had completed training in qualitative research prior to conducting interviews, and had experience of working with people with dysarthria. V.F. was a white British female, and had completed training in qualitative research prior to data analysis as part of her MSc course. They were supervised by an experienced qualitative researcher (V.L., white British female, PhD) and a clinical academic with some qualitative research training and experience (R.G., white British female, PhD, DClinPsy). Only R.G. had in-depth knowledge and experience of ACT.

C.R. and K.W. had built a relationship with some plwMND and all therapists prior to the interviews through engagement in the feasibility study. R.G. had established prior relationships with therapists through the provision of training and supervision in the feasibility study, while V.F. and V.L. had no prior or ongoing relationships with plwMND or therapists. C.R. and V.F. were not involved in earlier phases of the feasibility study and so were able to conduct interviews and initial data-driven analyses with a relative independence from expectations of therapy. K.W. was involved in earlier phases of the feasibility study, but only conducted three interviews and was not involved in data analysis. To mitigate the risk of a positive bias in plwMND and therapists' reporting, the importance of sharing both positive and negative experiences of intervention receipt or delivery was emphasised to all participants prior to and during the conduct of interviews.

Increasing engagement with plwMND and therapists throughout the analysis period enhanced C.R.'s understanding of the nuances of MND and of individual variations in experiences. This, in turn, enabled better contextualisation of the data and resulted in subsequent recoding into later themes. As increasing engagement with plwMND and therapists may have served to increase C.R.'s expectations of therapy, she frequently re-engaged with transcribed interviews to ensure that analyses remained rooted in the data. As R.G.'s possible allegiance to ACT may have influenced interpretation of data, she was only involved in the theme development stages. Participants were not given information about the researchers' personal goals or reasons for conducting the research.

Results

Figure 1 shows the recruitment flow of participants in the study. Table 3 displays the demographic and clinical characteristics of 14 plwMND who completed interviews. The average age of plwMND was 59.6 years ($SD = 12.4$, range 31–73 years), with all self-identifying as white/white British ($n = 14/14$) and just over half self-identifying as male ($n = 8/14$). Participants reported being most commonly diagnosed with the ALS variant of MND ($n = 10/14$).

The demographic and professional characteristics of 11 therapists who completed interviews are shown in Table 4. Therapists were primarily female ($n = 10/11$) and had been qualified for an average of 7.8 years ($SD = 4.1$, range 3–17 years). All therapists were qualified as clinical psychologists ($n = 11/11$), and the majority were employed as clinical psychologists at varying levels of seniority ($n = 8/11$).

Qualitative findings

Four over-arching themes were identified: (1) an appropriate tool to navigate the disease course; (2) the value of therapy outweighing the challenges; (3) relevance to the individual; and (4) involving others. Although both plwMND and therapists provided a perspective on each of these themes, we highlight in the findings those instances where one group gave particular emphasis or attention to a theme/subtheme.

Table 3. Demographic and clinical characteristics of plwMND

	n (missing *n*, %)	Mean (*SD*) or *n* (%)
Sex	14 (0, 0%)	
Male		8 (57%)
Female		6 (43%)
Mean age (years)	14 (0, 0%)	59.6 (12.4)
Age range (years)	14 (0, 0%)	
30–39		2 (14%)
40–49		0 (0%)
50–59		2 (14%)
60–69		8 (57%)
70+		2 (14%)
Ethnicity	14 (0, 0%)	
White/white British		14
Mean years of education	14 (0, 0%)	13.8 (3.7), range 10–21
Employment status	14 (0, 0%)	
Employed – paid		3 (21%)
Employed – voluntary		1 (7%)
Retired		6 (43%)
Not in employment		4 (29%)
Relationship status	14 (0, 0%)	
Married		13 (93%)
Single		1 (7%)
Probable or definite MND	14 (0, 0%)	
ALS		10 (71%)
No MND variant specified		4 (29%)
Mean months since symptom onset	12 (2, 14%)	55.2 (49.4), range 11–166
Mean months since diagnosis	13 (1, 7%)	25.1 (32.7), range 1–107
Mean rating of speech on ALS-FRS-R*	14 (0, 0%)	3.5 (0.7), range 2–4
Number with a self-reported mental health diagnosis	14 (0, 0%)	1 (7%)
Number prescribed psychotropic medication	13 (1, 7%)	3 (21%)
Fluoxetine		1 (7%)
Citalopram		1 (7%)
Amitriptyline		1 (7%)

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease.
*Self-reported ratings of speech on the ALS Functional Rating Scale-Revised (ALS-FRS-R; 4 = no change and 0 = unable to communicate verbally) at 6 months follow-up in the feasibility study.

Table 4. Demographic and professional characteristics of therapists ($n = 11$)

	Mean (*SD*) or *n* (%)
Sex	
Male	1 (9%)
Female	10 (91%)
Clinical qualification	
Doctorate in clinical psychology	10 (91%)
Clinical psychology (non-UK)	1 (9%)
Mean years since clinical qualification	7.8 (4.1)
Main occupational role	
Senior/lead/principal/highly specialist clinical psychologist	5 (45%)
Clinical psychologist	3 (27%)
Senior/lead/principal/highly specialist neuropsychologist	1 (9%)
Neuropsychologist	1 (9%)
Lecturer	1 (9%)

Theme 1: An appropriate tool to navigate the disease course

The first theme identified was ‘an appropriate tool to navigate the disease course’, which captured different aspects of the acceptability of ACT for plwMND within three subthemes: (i) ACT seen as appropriate given the disease prognosis; (ii) better understanding of ACT exercises than overall ACT philosophy; and (iii) the importance of a variety of ACT exercises to meet varied needs and preferences.

(i) ACT seen as appropriate given the disease prognosis

All participants felt that ACT was a suitable therapy for plwMND and could be an effective tool given the physical deterioration seen in MND and the potential for this to negatively impact on psychological wellbeing.

> '*The thing I liked about it was that it was clearly designed for people in my situation. Someone had thought about it and thought, well what can you say to somebody with MND that would be helpful to them? In a nutshell it's basically, the message is that you can either have the illness and be drawn into it and gradually become absorbed by it all, or you can say, well I've got the illness but that doesn't necessarily have to rule my life entirely. I can detach from the tendency to get drawn into it . . . But I think the major thing was that I felt that someone had designed it specifically for my kind of issues really, that's what made it work. So it wasn't like your average CBT or whatever, it was designed specifically for someone with MND.*' (P7, age 68, M)

A number of plwMND valued the intervention being focused on them as an individual with the disease, while one person situated the importance of the intervention within the limited treatment options that are currently available for plwMND.

> '*Well, I think it was all very personal. It was aimed at me. It was focused on me and what my goals are and what I'm not able to do any more and how I can cope with those feelings of frustration etc. So, I think it was pretty much focused on me as an individual to deal with this disease.*' (P1, age 68, F)

> '*I just feel that this is a very positive way forward for motor neuron disease sufferers. I mean, like I said, there is only one drug out there and not everybody . . . I mean, I don't take the drug because it affected me. So you're just plodding along, hoping you're doing the right thing and I just think this is a positive way forward. That there's a support, something that's going to be supportive to MND sufferers.*' (P4, age 67, F)

Therapists expressed that the philosophy of ACT felt appropriate considering the poor disease prognosis (i.e. an unchangeable, worsening situation requiring ongoing acceptance, openness and adaptation rather than simply 'an adjustment and then you carry on').

> '*I think that the ideas . . . We can't change the MND. The MND is there and it will progress. But what we can do is we can help you to live your life in the best possible way in line with your values . . . is a really powerful message. And I think that if the person is able to take that on emotionally and cognitively, then it is very freeing for them. Because it helps them to think about look, I can, the MND is going to happen. I can't stop it. So, I can either live my life all consumed by it and not doing the things that are important to me, or I can live my life doing the things that at the moment I'm able to do.*' (T6, F)

Therapists also suggested that ACT is preferential over other psychological therapies such as traditional cognitive behavioural therapy or problem focused therapy as it does not focus on trying to eliminate difficult internal experiences or problems.

> '*I think for me there's something about ACT that just feels a little bit more . . . It's probably not entirely accurate, but it feels less self-blaming or less that you should get rid of things. It feels a little bit more realistic in the sense that this is a really difficult diagnosis and you are going to feel difficult emotions in line with that and that's okay. We don't need to try and get rid of that, but we can help you live a life that's still meaningful. For me that feels a little bit more realistic and takes a lot of pressure off people.*' (T1, F)

A few therapists commented on how the timing of therapy and where it fits in a person's journey with MND (e.g. with respect to adjustment to the diagnosis) needs to be carefully considered. For example, it was suggested that if ACT is offered too close to diagnosis then denial/avoidance may impede engagement in therapy. All but one person with MND said that they would recommend ACT for those living with the condition.

> '*I think there probably needs to be some thought about the timing of the therapy and where it fits with somebody's journey with MND. I don't really know what the answer to that is, but I think people's experience of the therapy and how they use it can be very different, depending on how early on they are in terms of receiving their diagnosis and how physically affected they are.*' (T9, F)

(ii) Better understanding of ACT exercises than overall ACT philosophy

PlwMND reported variability in their understanding of the concepts and rationale of ACT. Understanding was facilitated by congruence with personal philosophy or by personal experiences such as profession. Barriers to understanding included the use of technical language and ambiguity in the aims of ACT. PlwMND often reported better understanding of specific ACT exercises rather than the overall philosophy of ACT. However, the ability to verbally describe ACT concepts was not necessary for reported positive experiences.

> '*I think I was quite easy. As I say, I could understand some of the elements being difficult for other people.*' (P12, age 65, F)

> '*It was difficult because I didn't know what you were trying to achieve, you see? So my answers may have been complete rubbish, because I didn't understand the question.*' (P11, age 61, M)

Therapists felt that most plwMND had a good understanding of ACT exercises, which was facilitated by the ACT diagram (see Supplementary material: File 4) and experiential practice across sessions, with understanding of ACT concepts being more mixed.

> '*The diagram was quite helpful, just to have a pictorial demonstration that's not wordy. No, I think they got it quite easily actually. And then session by session you'd just be reinforcing a different part. And I think that made sense.*' (T3, F)

> '*I think they related to the concepts more. The concept of values, the concept of mindfulness and being present. I think at the end of it, if you were to say to them, what is ACT therapy or what do you like about ACT therapy, I don't know if they could have answered that.*' (T9, F)

(iii) The importance of a variety of ACT exercises to meet varied needs and preferences

There was variability in the degree to which plwMND connected with and/or were able to implement ACT exercises (see Supplementary material: File 5 for a description of these) in their daily lives. For example, some plwMND connected with the mindfulness principle behind a present-moment awareness exercise, the centring exercise, while others appreciated it as a chance to relax, and some reported they did not ‘get it’ and subsequently did not find it useful. Others identified the ‘Leaves on a stream’ exercise and the ‘Labels’ exercise as the easiest to engage with and apply to their daily lives. Therapists additionally commented on the usefulness of focusing on values in the sessions. Some plwMND reported that certain metaphors (such as the ‘house and furniture’ and ‘passengers on the bus’ metaphors) resonated with them and helped them to reflect on their experiences.

> ‘*There were some others where you put your thoughts on a tag and you can just hang them and you can look at them. I could see that it was the same idea as placing thoughts on leaves. But placing thoughts on name tags didn’t have the same impact as the one that included the leaves for some reason. I don’t know why.*’ (P10, age 51, M)

> ‘*And the other aspect was the labelling, having labels. It was quite a practical exercise and visualising that your MND is just a label on you and it’s not you. You are you. You know, I am still me and it’s another aspect.*’ (P4, age 67, F)

Therapists reported that ACT exercises that were more concrete or practical were more successful or easier to deliver.

> ‘*I think the exercise which was quite structured and less abstract, like the label exercise or the value committed action exercise, and also passenger on the bus exercise. These exercises that have more explicit activities worked better than more abstract methods.*’ (T8, F)

Ultimately, therapists and plwMND valued a range of ACT exercises to suit the needs and preferences of the individual and ensure a greater fit between the individual and ACT exercises (rather than a ‘one size fits all’ approach).

> ‘*I think the variation of exercise, like I said, because some suit some people, some suit others. And you draw out what’s suitable for you. So it wasn’t rigid, it has a flexibility about it. So I think that’s important.*’ (P4, age 67, F)

Theme 2: The value of therapy outweighing the challenges

The next theme identified was ‘the value of therapy outweighing the challenges’, encompassing the experience of receiving ACT for plwMND. Five subthemes were identified: (i) positive experiences despite varied expectations; (ii) perceived benefits (now and in the future); (iii) the importance of the therapeutic relationship; (iv) therapy as emotionally challenging; and (v) the challenge of discussing sensitive topics.

(i) Positive experiences despite varied expectations

Initial expectations of therapy amongst plwMND ranged from low to high, but could change throughout the duration of therapy. Expectations were sometimes linked to prior experience or pre-conceived notions of therapy, with only a few hoping for a ’magic wand’ solution or miracle. Although expectations varied, most participants reported a positive experience of ACT. In some cases, an incongruence between expectations and actual experience of therapy contributed to feelings of disappointment (in the case of higher expectations). However, for most plwMND, this incongruence contributed to feelings of satisfaction, with experiences of therapy exceeding expectations of it.

> ‘*I didn’t really have any expectations because I had no idea at all what it was going to be.*’ (P1, age 68, F)

> ‘*Oh, well it exceeded it* [expectations of therapy] *enormously because to be honest with you I wasn’t expecting it to make any difference at all really … But at the same time, it’s not a magic wand and it won’t necessarily solve everything as I thought it might.*’ (P7, age 68, M)

> ‘*At first, I thought oh, it’s going to be one of these preachy things, I don’t know whether I should do it. But after the second time and she said are you going to come back next week? I went oh, yeah. I was more relaxed.*’ (P9, age 62, M)

(ii) Perceived benefits (now and in the future)

Most plwMND and therapists reported a positive impact of ACT, with benefits either being experienced at present or anticipated to be helpful in the future as their condition deteriorates. Perceived emotional benefits reported by plwMND included improved coping, coming to terms with or being more accepting of MND and aids/adaptations, having a more present-focused, positive outlook on life, feeling more relaxed, thinking differently about things and being able to acknowledge and share their feelings with others. Behavioural changes included increased engagement in leisure and social activities, relationships and healthcare planning.

> ‘*Well initially it was a big change, it was a step change. People said, you seem a lot better, you seem to be coping with everything. I explained, well I am and it’s due to this sort of input that I’ve had that’s helped me. Which I wasn’t really expecting and I didn’t really think it would work, but to my surprise it did … Yes, a bit more than that, it has slowed my rate of decline a little bit.*’ (P7, age 68, M)

> ‘*So I think, all in all, the therapy has put me in a better place, a better frame of mind.*’ (P11, age 61, M)

> ‘*I don’t think it’s made a big difference to me. I enjoyed the challenge and I’ve got some takeaways from having done it. And one of the things I guess is that I’ve got some satisfaction out of doing it. And I have brought away one or two of those techniques that* [therapist] *taught me that I have brought into daily life, if you like, which I found quite helpful. And as my condition deteriorates, which it’s likely to do over time, it’s given me some tools that perhaps I’ll be able to use more in the future to help me get over difficult situations.*’ (P5, age 73, M)

> ‘*And then one of the biggest changes I think he made was around his openness and communication. So he had hidden the sort of physical and emotional impact of MND from his wife and from his employers. And then he completely told her everything about what sensations he had in his body and what he was thinking about, and the same with work. And that was huge for him, really huge. And it made a big change. It allowed work to be a better support and help him to adapt and allowed his wife to know, you know, what she already knew but what he wasn’t saying. So that was amazing.*’ (T3, F)

> ‘*I think even if the person might not have any psychological issues at the moment, I believe it will be really helpful in the future. And also, I saw my client benefiting from ACT, particularly preparing for future challenges and also preparing for the things that might happen in the future because of the condition. And I think that’s particularly important for this population. And ACT has a lot to offer for those processes which can be very challenging.*’ (T8, F)

PlwMND often associated a lack of perceived benefits or changes with a lower perceived need for therapy at the outset. Some plwMND remarked that therapeutic benefits were contingent on the effort and time put in with respect to home practice completion and session engagement.

> '*I think that you've got to be pretty open-minded. You've got to be prepared to work quite hard, I think, but if you are able to do that and see the wood for the trees, you'll come out of it with something.*' (P7, age 68, M)

(iii) The importance of the therapeutic relationship

PlwMND emphasised the importance of having 1:1 time with a professional who had some knowledge of MND (which was similarly echoed by one therapist), who was able to tailor the content and pace of the sessions according to their needs and explain complicated concepts. They also valued being able to talk openly to their therapists and feeling listened to, which positively contributed to the overall therapeutic experience. Therapists valued the quality of the therapeutic relationship (e.g. the ability to develop a good therapeutic rapport with the participant) and suggested that this facilitated the person with MND's engagement in ACT.

> '*It's not often you get the chance to speak to a professional for a full hour – and I sometimes went over the hour – and open up your heart and mind. So I think that's a very positive thing for people in my position.*' (P4, age 67, F)

> '*I think it's really important, as I say, that it's face to face and you have a personal relationship with the therapist. I think that's really important. And that the therapist gives you time to keep up, if you know what I mean, or to catch up with them, because in these matters, they're a lot cleverer than I am, sort of thing.*' (P5, age 73, M)

> '*And then obviously the stuff about the relationship between myself and the patient and setting up that first session and just getting that sort of buy in really helps with engagement.*' (T3, F)

(iv) Therapy as emotionally challenging

PlwMND and therapists highlighted emotional challenges to engaging in therapy, both for plwMND and therapists, and the difficulty of addressing distressing or painful issues. However, plwMND also valued the benefit of discussing these issues with the therapist. Therapists noted that uncomfortable or emotionally draining moments were not necessarily detrimental to the progress of therapy.

> '*I think some of it's quite challenging, but I wouldn't say that it wasn't acceptable.*' (P5, age 73, M)

> '*It was quite emotional on a number of occasions. Very, very emotional in actual fact. But I did find it useful. I certainly did.*' (P1, age 68, F)

> '*I think from a kind of personal perspective as a therapist sometimes doing this kind of work where you're staying with the difficult thoughts and feelings is difficult. You know, it can be quite, quite painful and emotional really to kind of go there with someone and stay with it and expect them to stay with it longer than they perhaps would have or would want to.*' (T4, F)

(v) The challenge of discussing sensitive topics

A few plwMND and one therapist identified suicide, self-harm and sexual intimacy as areas that may feel difficult to discuss in therapy due to this feeling invasive or irrelevant within the context of ACT. However, they also considered that sensitive discussion of these issues could prove beneficial.

> '*Well it was just that particular statement at the beginning of every week that I said* [suicide]. *That was the only thing really that I felt was invasive.*' (P4, age 67, F)

> '*I don't think there was anything that they found unacceptable, no. I think, and if you were around asking about suicidal or self-harm, it wasn't that they were offended by that, but they just felt like it was irrelevant and almost I could see a roll of the eyes and the head again.*' (T5, F)

> '*I can't say that there's a lot to be concerned about there. We talked about intimacy a bit, which is a sensitive subject. But it was helpful to talk about it. Some people might not feel comfortable with that.*' (P6, age 70, M)

Theme 3: Relevance to the individual

The next theme was 'relevance to the individual', referring to factors that stemmed from individual preferences and experiences. Four subthemes were identified: (i) congruence with personal philosophy or beliefs; (ii) perceived need for therapy; (iii) impact of previous experiences of therapy; and (iv) personal resonance and continued practice beyond therapy.

(i) Congruence with personal philosophy or beliefs

Many plwMND alluded to a high congruency between the perceived principles of ACT and their own personal philosophy or beliefs, contributing to an enhanced understanding and experience of ACT.

> '*I think unlike any sort of … I had a little bit of therapeutic help in the past, but unlike any of the previous sort of sessions, I felt that this was particularly relevant to me, you know. It really did sort of chime. I really did get it, you know, quite well.*' (P7, age 68, M)

A few plwMND felt that ACT 'wasn't for them', as they already had a 'positive outlook' and thus ACT did not add anything new to their outlook or experience. Approximately half of plwMND remarked that ACT might be more beneficial for someone who was coping less well than they were or was more 'negative' in their outlook.

> '*Well, I could see what it was getting you to try to do, but it just … I'm a sort of positive person anyway so it didn't really do much for us.*' (P3, age 65, F)

> '*I would say particularly someone who's got more difficulties than we have. Because some of the people that we meet through various MND get-togethers definitely don't cope as well as we do and they need help more than we do. The question is whether they would accept the therapy or not because they may be so negatively disposed to life that they feel that it couldn't help. But I certainly feel it could help others.*' (P6, age 70, M)

Therapists suggested that a person's existing coping strategy and personal philosophy could lead to challenges in ACT, with many identifying avoidance (e.g. of thoughts and emotions) as a common challenge for therapy.

> '*I think it's the default for us in society. We think there should be a way of getting rid of these things.*' (T2, M)

(ii) Perceived need for therapy

Therapists noted that some plwMND with a lower perceived need for psychological intervention (for example, those who were taking part due to their desire to 'help out with research') were less inclined or willing to engage with therapy on a personal level. Other therapists noted that a lower perceived need for therapy at the start of the sessions did not necessarily stop some plwMND from benefiting from ACT.

> '*I think working with him was quite rewarding because even though he came into it thinking he didn't really need this kind of support, I think he and his wife both got a lot from it.*' (T4, F)

(iii) Impact of previous experiences of therapy

Therapists noted that previous experiences of other therapies impacted on engagement with ACT. For example, previous experiences in relation to cognitive restructuring (i.e. thought challenging) were incongruent with ACT principles and could act as a barrier to understanding of ACT concepts and hence treatment outcome. A few plwMND commented on how their previous experiences of other therapies impacted on their expectations of ACT, with ACT typically surpassing their expectations.

> '*The only thing that I did notice is that he is someone who's had quite a lot of therapy in the past and so he did veer towards thought challenging quite a lot. He's obviously had quite a bit of CBT. So it is understandable that he would return to that way of problem solving. So I had to keep bringing him back to the idea of acceptance and willingness, rather than trying to get rid of the thoughts.*' (T6, F)

> '*I think that notion of accepting the difficult stuff. She'd had previous experience of hypnosis and she was quite into complimentary therapies. And I think she came into the therapy heavily invested in the idea that these things can be taken away and, as I say, I don't think she fully accepted that sometimes we just have to sit with the difficult things and find a space for them. It wasn't a problem for her ultimately because what she was doing was broadly working and she did take on board the new methods. But I think that was the most challenging part for her.*' (T2, M)

> '*The reason being is I'm a cynic when it comes to therapy. I've had counselling, a few different counsellors I've been with, and most of the time I don't think it . . . I'm very much a cynic that just talking about it doesn't really do anything. I'm an actions person. And so, when I started it, I didn't have high expectations of it. So, in a way, having the therapy I try on myself . . . probably it was more than I was expecting I guess because I was expecting to gain nothing out of it.*' (P2, age 55, M)

(iv) Personal resonance and continued practice beyond therapy

Some plwMND reported continued use and practice of ACT skills and exercises beyond the therapy sessions. Unsurprisingly, these tended to be those that they had reported connecting with or that had resonated with them during the therapy sessions.

> ‘*I definitely think it was positive. I really enjoyed my time with the therapist. It was very good and I took some things out of it which are helping me now.*’ (P8, age 37, M)

> ‘*The mindfulness thing, I still practise it today. And the labels exercise, where bad things about my condition were written on labels and then removed from me, I've remained with that.*’ (P11, age 61, M)

Theme 4: Involving others

The final theme identified was ‘involving others’, which considered the wider social network affected by MND. It consisted of two subthemes: (i) the needs of others; and (ii) support from others.

(i) The needs of others

For a few plwMND, it was important to recognise the role of family, particularly the impact of MND on family members and the importance of including them in therapy. The impact of MND on the family was also recognised by a few therapists. One person with MND felt that family members should be offered their own individual therapy.

> ‘*Because at the end of the day, my thoughts are my family are actually going to end up suffering far more than I'm suffering because they have to live after I'm not here. So their pain is continuing after I'm not here. So my thoughts were that my family members surely would have benefited from being part of the therapy as well.*’ (P10, age 51, M)

> ‘*His wife came as well and I think that was quite beneficial in a sense that you know motor neuron disease has effect on the person but also has a real knock-on effect for the whole family and extended family as well.*’ (T7, F)

> ‘*But just about the immediate family, that was something that I did wonder about because I did think there should have been some mention about how your spouse or your family are coping with it as well. And possibly anything one could do to discuss it with them as well and perhaps have some talking therapy for them. It's just a thought.*’ (P1, age 68, F)

(ii) Support from others

Therapists thought that involving family could be beneficial in facilitating therapeutic engagement, particularly with respect to supporting the completion of home practice and attending sessions.

> ‘*And also because her husband, who is a carer, attended that whole session, they were saying that it was helpful for them to have time to discuss and work on the home practice together because it helped them to start thinking about the future and not avoiding to think about what might happen in the future. So, I think it's not just her, but also her carer said that he found it very helpful.*’ (T8, F)

> *'And I think there was a sense that if somebody else is present with you in the therapy, that they're not necessarily benefiting, but they're there to walk that journey with them . . . So I think it probably helped with engagement, the fact that the door was open to join the sessions as well.'* (T7, F)

However, a few therapists noted that balancing this could be challenging as the family member may bring additional emotions and issues to the session.

> *'I think that can be a double-edged sword as well. Because then you've got to manage another person in the room and another person with all their own anxieties and worries and fears about the future. And often there's a lot of really heightened emotion when you're working with people with MND. And I generally, in my normal clinical practice, I do see people with their relatives and sometimes that can actually be even more difficult than when you've got them on their own. There's pros and cons to that. But I think it can improve engagement.'* (T6, F)

Discussion

This study aimed to qualitatively explore the acceptability of ACT for plwMND, both from the perspective of plwMND receiving the therapy and therapists delivering it. Four over-arching themes were identified: (1) an appropriate tool to navigate the disease course; (2) the value of therapy outweighing the challenges; (3) relevance to the individual; and (4) involving others. Key implications in relation to these themes are discussed below.

Findings demonstrated that plwMND and therapists perceived ACT to be an appropriate psychological intervention for plwMND, providing support for previous recommendations for this population (Pearlman and Thorsteinsson, 2019; Weeks *et al.*, 2019). Both therapists and plwMND considered the potential utility of ACT in coping with future disease progression as crucial to its value, supporting the perceived acceptability of ACT across the disease course. These findings are consistent with previous reports of the acceptability of ACT for people with life-limiting illnesses and neurological conditions, including advanced cancer and multiple sclerosis (Giovannetti *et al.*, 2020; Hulbert-Williams *et al.*, 2021). They are also in line with qualitative feedback showing that mindfulness-based interventions are acceptable for those with neurodegenerative diseases of the motor system, including MND (Marconi *et al.*, 2016), Parkinson's disease (Bogosian *et al.*, 2022) and premanifest Huntington's disease (Eccles et al., 2021). This latter point is pertinent given that mindfulness or present-moment awareness is one of the hypothesised core processes within ACT. Taken together, current and previous studies support the suitability of 'third wave' psychological approaches, such as ACT and mindfulness-based interventions, for those with neurodegenerative diseases of the motor system.

It has been previously suggested that perceived changes resulting from psychological therapy are mediated by factors such as whether the therapy made sense to the individual and whether therapeutic strategies and perspectives were personally resonant (Brooks *et al.*, 2021). Themes and subthemes identified in the current study are partially consistent with this. For example, our findings showed that plwMND did not have to have a cognitive or verbal understanding of ACT concepts or philosophy to experience beneficial effects, but those who described a personal resonance with or an experiential understanding of ACT exercises reported more positive outcomes. This is consistent with ACT's theoretical underpinnings (Hayes *et al.*, 2012), which note that one can act with psychological flexibility without being able to verbally explain the process, theory, or philosophy, and instead emphasises an experiential understanding of ACT. That is, people do not need to be able to make verbal or cognitive sense of ACT (i.e. they do not need to 'get it') in order to benefit from it. This suggests that helping plwMND to develop a willingness to engage openly with therapy and gain an experiential understanding of ACT exercises and principles, even if it does not make sense to them, is important.

Given ACT's emphasis on an experiential rather than verbal understanding, finding ways to enhance the experiential understanding of ACT principles is obviously crucial. Facilitators of this in plwMND included using concrete metaphors and exercises and using non-technical terminology, supporting previous recommendations for older people (Lawrence *et al.*, 2019). In some plwMND, previous experiences of therapy acted as a barrier to experiential understanding and implementation of ACT principles (e.g. due to incongruent psychological strategies across different therapeutic approaches). Differences between ACT and other psychological approaches can create confusion and lead to alienation from the rationale for ACT (Bendelin *et al.*, 2020). Therefore, providing a clear and consistent rationale for ACT early in therapy (Constantino *et al.*, 2012) may be one way of overcoming this barrier.

Most plwMND and therapists reported benefits of ACT, with benefits either being experienced at present or anticipated to be helpful in the future as the disease progresses. Perceived benefits for plwMND included emotional changes such as improved psychological adjustment to MND and acceptance of aids/adaptations, cognitive changes such as 'thinking differently about things', and behavioural changes such as increased engagement in leisure/social activities and future planning. Previous qualitative studies of ACT in other populations have described similar findings (Bendelin *et al.*, 2020; Giovannetti *et al.*, 2020; Hulbert-Williams *et al.*, 2021; Large *et al.*, 2020). Furthermore, the finding of improved psychological adjustment to MND and acceptance of aids/adaptations with ACT is consistent with a previous study of psychological flexibility in this population (Pearlman and Thorsteinsson, 2019). This study showed that greater psychological flexibility, which is what ACT aims to increase, predicted greater understanding and acceptance of percutaneous endoscopic gastrostomy in people living with ALS.

Although previous research has shown that higher expectations of therapy are associated with better outcomes (Constantino *et al.*, 2011), most plwMND reported neutral initial expectations of therapy, and yet still reported a positive experience of ACT. For some, expectations of therapy varied across the course of therapy, as has been reported by others (Brooks *et al.*, 2021). Some plwMND described how ACT required more work and committed input than anticipated; an observation that is not unique to ACT, but which applies to experiences of psychological therapy in general (Brooks *et al.*, 2021). PlwMND who engaged actively and with personal investment reported the greatest changes, including adoption of exercises and changes to one's outlook and perceptions of coping, consistent with previous findings (Bendelin *et al.*, 2020). The fact that all plwMND reported an altruistic motivation for engaging in ACT as part of the feasibility study, rather than a perceived 'need' for psychological therapy, may have influenced personal investment in therapy. Alternatively, it may be that those who did not perceive a need for therapy (e.g. due to fewer adjustment issues) may have experienced fewer opportunities to implement therapeutic techniques in their daily lives. This may also have contributed to some people's reflections that ACT would be particularly helpful for those who they perceived as coping less well with MND than they were.

Therapists having knowledge and prior experience of MND has been previously identified as an important pre-requisite for psychological therapy for this population (Rabbitte *et al.*, 2015; Weeks *et al.*, 2019), as this can help to provide a 'safe space' for emotional exploration (Rabbitte *et al.*, 2015). Therapists being knowledgeable in MND was similarly highly valued by plwMND in the current study and considered to positively contribute to the therapeutic experience. This emphasises the importance of ACT, and more broadly psychological therapies, being delivered to plwMND by those with specialist MND knowledge (such as those embedded within MND multidisciplinary teams) rather than those based in generic mental health services.

A sense of personal relevance or congruence between ACT principles and an individual's personal philosophy contributed to the experience of ACT in the current study. Some plwMND described a feeling of 'resonance' or a natural engagement with ACT exercises, facilitated by their personal philosophy or beliefs. Others felt that their existing 'positive' outlook resulted in limited additional benefits from ACT, potentially reflecting a misunderstanding of ACT principles. plwMND attributed the flexibility of ACT, which could be tailored to the individual by therapists, to the therapy's success. This is important to note given that: (i) others have highlighted that the complexity and progression of MND necessitates flexibility in therapy (Rabbitte *et al*., 2015; Weeks *et al*., 2019); and (ii) previous findings have shown that the lack of tailoring diminishes the perceived value of therapy for recipients (Brooks *et al*., 2021).

Finally, although therapists and some plwMND felt that involving family in therapy could be beneficial for all parties, some plwMND valued 1:1 sessions and the 'freedom' that came with speaking to a stranger. This supports previous recommendations to consider both the person with MND's social network in therapy (Harris *et al*., 2018) and their preferences with respect to involving others in therapy (Weeks *et al*., 2019). One person with MND highlighted the need for family members to be offered their own psychological therapy. There is currently little guidance as to what this should be, due to the lack of high quality research in this area (Cafarella *et al*., 2022). ACT offers promise as a psychological intervention suitable for caregivers of plwMND, in addition to plwMND, given that it has been found to be acceptable and feasible in caregivers of people living with dementia (Kishita *et al*., 2022). However, reports of a low adherence rate, coupled with no effects of treatment on primary or secondary outcomes, in an RCT of a blended ACT-based intervention *vs* waiting list in caregivers of plwMND (De Wit *et al*., 2020) suggests that any future research should carefully consider how to optimise intervention engagement in this population prior to assessing effectiveness.

Clinical implications

Key implications of the qualitative findings with respect to optimising the delivery of ACT to plwMND are shown in Table 5. ACT for plwMND should accommodate the nature of the disease and individual characteristics to support expectations and experiential understanding of ACT. The rationale for ACT should be introduced early on and reiterated throughout therapy, and this should be tailored to recognise varied motivations to engage in therapy, expectations of therapy and personal philosophies. Some consideration should be given to whom ACT should be offered to (e.g. those for whom treatment of emotional distress and/or adjustment issues is the aim *vs* those for whom prevention of such issues is the aim), and when ACT should be offered in the disease course (e.g. immediately post-diagnosis *vs* 6 months after diagnosis). It is important to recognise that a cognitive or verbal understanding of ACT principles is not necessary to achieve benefits. However, non-technical terminology and the use of concrete exercises and metaphors may facilitate an experiential understanding of these. Therapy should also include a willingness to openly explore sensitive or emotive topics such as suicide and sexual intimacy. Therapist pre-requisites include having knowledge of MND and how to tailor ACT exercises and metaphors to individual needs and preferences. Involving family members may facilitate engagement in ACT for some plwMND.

Research implications

It has been previously argued that ACT may be particularly beneficial for plwMND (Weeks *et al*., 2019). An uncontrolled feasibility study showed that ACT adapted for the specific needs of plwMND appears to be feasible to deliver and acceptable to this population, as indicated by good session attendance and high satisfaction rates, respectively (Gould *et al*., 2023). The clinical effectiveness of ACT adapted for plwMND for maintaining or improving quality of life was confirmed in a recent RCT (Gould *et al*., 2024). High session attendance and satisfaction rates again suggested the intervention was acceptable to plwMND. The qualitative results reported here build on previous evidence in providing further support for the acceptability of ACT adapted for plwMND. Future research should investigate moderators of treatment outcome in ACT for plwMND, including factors that have been identified here such as expectations and perceived

Table 5. Themes and subthemes with illustrative quotes and key implications

Theme	Sub-theme	Key implication(s)
(1) An appropriate tool to navigate the disease course	(i) ACT seen as appropriate given the disease prognosis	(1) Highlights the importance of ensuring that ACT is adapted as much as possible to the specific psychological, physical, communication and cognitive needs of the person with MND
	(ii) Better understanding of ACT exercises than overall ACT philosophy	(1) Explore the person with MND's experiential understanding of key concepts of ACT rather than focusing on a cognitive or verbal understanding of ACT (as they do not need to 'get it' in order to experience beneficial effects) (2) Adapt the use of ACT terminology to the individual (3) Provide a pictorial brief introduction to ACT at the start of therapy
	(iii) The importance of a variety of ACT exercises to meet varied needs and preferences	(1) Use concrete ACT metaphors and exercises as much as possible (2) Ensure familiarity with a range of written, verbal and imagery ACT exercises and metaphors in order to accommodate individual needs and preferences
(2) The value of therapy outweighing the challenges	(i) Positive experiences despite varied expectations	(1) Explore the person with MND's expectations about ACT at the outset of therapy (2) Ensure that the person with MND fully understands the aims of ACT at the outset
	(ii) Perceived benefits (now and in the future)	(1) Facilitate ongoing awareness of perceived benefits throughout therapy and positively reinforce any behavioural changes (2) Help the person with MND to explore how ACT skills may be beneficial both now and in the future
	(iii) The importance of the therapeutic relationship	(1) Ensure that plwMND are provided with opportunities to access psychological therapy
	(iv) Therapy as emotionally challenging	(1) Ensure that the person with MND is aware of the potential for ACT to be challenging and the potential for emotional distress at the outset of therapy (e.g. using the rollercoaster metaphor) (2) Ensure the provision of access to regular supervision for therapists
	(v) The challenge of discussing sensitive topics	(1) Provide a rationale for the discussion of sensitive topics such as suicide and self-harm or sexual intimacy
(3) Relevance to the individual	(i) Congruence with personal philosophy or beliefs	(1) Explore the person with MND's personal philosophy or beliefs within an ACT perspective (e.g. exploring workability of the personal philosophy or beliefs) (2) Help the person with MND to develop a willingness to engage openly with therapy and learn from the experience, even if it does not make sense to them according to their personal philosophy or beliefs
	(ii) Perceived need for therapy	(1) Help the person with MND to explore how ACT can be applied to their lives even if they are not experiencing difficulties (e.g. by focusing on personal growth alongside MND)
	(iii) Impact of previous experiences of therapy	(1) Consider how a person with MND's previous experience of therapy may affect engagement with ACT
	(iv) Personal resonance and continued practice beyond therapy	(1) Explore how the person with MND can apply techniques to their daily life to ensure continued practice beyond therapy
(4) Involving others	(i) The needs of others	(1) Consider offering joint sessions with partners, families or friends, with the consent of the person with MND, or consider offering them their own sessions
	(ii) Support from others	(1) Consider inviting a partner, family member or friend to support the person with MND during therapy, with the person with MND's consent

personal relevance of ACT, as well as perceived need for therapy, as a means of identifying who might benefit the most from this type of therapy.

Strengths and limitations

To the authors' knowledge, this is the first study to explore the qualitative experiences and reflections of plwMND receiving ACT and therapists delivering ACT to this population, addressing a recognised shortfall of therapy-specific and qualitative research in MND (Gould *et al*., 2015; Harris *et al*., 2018; Pagnini, 2013). Furthermore, insights from therapists served to contextualise reports from plwMND and enhance interpretation of the data.

However, there are several limitations of this study. First, the findings cannot be generalised to plwMND in more advanced stages of the disease (i.e. those with a need for gastrostomy or non-invasive ventilation) or those with co-morbid dementia due to our inclusion criteria. They can also not be generalised to those using augmentative and alternative communication devices as no plwMND reported using these in our study. Similarly, results cannot be generalised to a broader demographic population of plwMND and therapists given that the majority of plwMND self-identified as white/white British and only one therapist self-identified as male. Future studies should ascertain the acceptability of ACT in broader and more diverse populations of plwMND.

Second, it is important to recognise that our findings may be subject to a positivity bias. While interviews were conducted by a researcher who was independent from the person with MND's clinical team, some participants may have been unwilling to report negative experiences of therapy to the researcher, as noted by others (Holding et al., 2016). This may be particularly applicable to plwMND and therapists who had built a relationship with the researchers through participation in the feasibility study. Furthermore, it was not possible to explore experiences of ACT in those who withdrew from the feasibility study (due to withdrawing consent to be contacted) or declined an interview. Interviews with plwMND and therapists may have also been subject to an allegiance bias as a result of positive experiences of receiving and delivering ACT. Additionally, the degree of engagement in the intervention may have been influenced by high levels of motivation given that high levels of motivation to engage in research have been reported in previous studies of plwMND (Beswick *et al*., 2024). Consequently, future studies should seek to examine the acceptability of ACT in those who disengage from it, as well as engagement in ACT in real world or naturalistic settings.

Conclusions

PlwMND and therapists reported positive overall experiences of receiving and delivering ACT. Variations in experiences of ACT may be attributable to numerous factors, including differences in the perceived need for therapy, expectations about ACT and the perceived personal relevance of ACT. Future research and clinical practice should aim to recognise and account for these individual factors to optimise the delivery of ACT to plwMND.

Key practice points

(1) Adapted ACT was perceived as being acceptable to both plwMND receiving it and therapists delivering it.
(2) Value was particularly placed on the potential utility of ACT for helping plwMND to cope with future disease progression.
(3) Therapists having knowledge of: (i) MND; (ii) a range of ACT exercises and metaphors; and (iii) how to tailor ACT exercises and metaphors to suit individual needs and preferences was seen as crucial to the experience of ACT.
(4) Accounting for key implications of the qualitative findings may further improve the acceptability of ACT to plwMND.

Further reading

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Data availability statement. De-identified datasets will be available upon reasonable request, following publication of the study results. Emails should be sent to the corresponding author, stating the fields required and purpose of the request. Requests will be considered on a case-by-case basis and requestors will be asked to complete a data sharing agreement with the sponsor before data transfer. Data will be retained for 10 years following close of the study, before being destroyed. Data will not be publicly available due to the potential risk of compromising participants' privacy.

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