1 **Experiences of Acceptance and Commitment Therapy for people living with motor neuron disease**
2 **(MND): A qualitative study from the perspective of people living with MND and therapists**
3
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Conflicts of interest

The authors report there are no conflicts of interest to declare.

Data availability statement

Deidentified 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

77 10 years following close of the study, before being destroyed. Data will not be publicly available due
78 to the potential risk of compromising participants' privacy.
79
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86
87

88 **Abstract**

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

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

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

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

109

110 **Key words:** Motor neuron disease, Acceptance and Commitment Therapy, qualitative, acceptability

111 **Key learning aims**

- 112 To understand the views of people living with motor neuron disease (plwMND) and therapists on
113 Acceptance and Commitment Therapy (ACT) for people living with this condition.
- 114 To understand the facilitators of and barriers to ACT for plwMND.
- 115 To learn whether ACT that has been tailored to meet the specific needs of plwMND needs to be
116 further adapted to potentially increase its acceptability to this population.

117

118

119 **Introduction**

120 Motor neuron disease (MND) is a progressive neurological condition in which degeneration of motor
121 neurons in the spinal cord and motor cortex causes muscle wasting, stiffness and weakness. It affects
122 approximately 2-3 people in every 100,000 (Hardiman et al., 2017), and life expectancy is typically 2-
123 4 years following diagnosis (Goutman et al., 2022). There is no cure for MND, and riluzole, the only
124 disease-modifying treatment licenced in the UK, has limited efficacy (Miller et al., 2012).
125 Consequently, current treatments focus on symptomatic relief and reducing the negative impact of
126 the disease on quality of life.
127
128 Psychological distress, including depression and anxiety, is common in people living with MND
129 (plwMND). For example, a recent systematic review reported a pooled prevalence rate of 34% for
130 depression, with rates varying depending on the assessment tool used (Heidari et al., 2021). Similarly,
131 prevalence rates of up to 30% have been reported for anxiety (Kurt et al., 2007). Psychological distress
132 in plwMND is associated with numerous factors, including poorer quality of life (Edge et al., 2020; van
133 Groenestijn et al., 2016), increased hopelessness (Paganoni et al., 2017) and increased risk of suicide
134 (Fang et al., 2008). Substantial levels of psychological distress and burden have also been reported in
135 caregivers of plwMND due to the nature of MND and the challenges it brings (Aoun et al., 2013).
136 Despite calls to address psychological distress in both MND healthcare and as a focus of research
137 (Harris et al., 2018; Pagnini & Simmons, 2018), evidence-based guidance on specific psychotherapeutic
138 interventions for plwMND is limited due to a paucity of high-quality research studies (Gould et al.,
139 2015; Oh et al., 2024; Simpson et al., 2021; Zarotti et al., 2021).
140
141 One form of psychological therapy that offers potential promise for managing psychological distress
142 and quality of life in plwMND is Acceptance and Commitment Therapy (ACT) (Hayes et al., 2012). ACT
143 encourages the development of psychological flexibility through a combination of acceptance and
144 mindfulness-based strategies in conjunction with motivation and behavioural change strategies. Its

145 focus on engagement in values-based living, alongside whatever negative thoughts, emotions and
146 physical sensations are experienced, distinguishes it from conventional Cognitive Behavioural Therapy
147 (CBT) where the focus is more on alleviating distress or symptoms. This alternative focus means that
148 it may be a particularly suitable approach for those with chronic or life-limiting conditions.
149
150 In line with this, ACT has an established evidence base in a range of mental and physical health
151 conditions, including chronic pain, depression, anxiety, substance use and transdiagnostic groups
152 (Gloster et al., 2020). In contrast, evidence of its effectiveness in neuromuscular and neurological
153 disorders is limited, but growing (Graham et al., 2016). For example, statistically significant
154 improvements in quality of life, depression and anxiety at 9-weeks follow-up were reported in a
155 randomised controlled trial of ACT plus usual care for chronic muscle diseases in comparison to usual
156 care alone (Rose et al., 2023). Similarly, significant improvements in psychological quality of life were
157 reported in a small pilot randomised controlled trial of ACT for people living with Parkinson's disease
158 in comparison to treatment-as-usual (Ghielen et al., 2017). Additionally, improvements in
159 psychological distress, trait mindfulness, values-based living and psychological flexibility have been
160 reported in a service evaluation of ACT groups for people living with neurological conditions (Bowers
161 et al., 2021).
162
163 With respect to the potential acceptability of ACT for plwMND, a series of recommendations have
164 previously been made with respect to how psychological interventions can be adapted for the specific
165 psychological, physical, cognitive and communication needs of this population (Weeks et al., 2019).
166 These recommendations were based on feedback from a series of qualitative interviews with
167 plwMND, caregivers and healthcare professionals. They were used to develop an ACT intervention,
168 tailored to the needs of plwMND, which was subsequently evaluated within an uncontrolled feasibility
169 study (Gould et al., 2023). ACT appeared to be both feasible to deliver and acceptable to plwMND, as
170 indicated by high session attendance and satisfaction rates. Furthermore, possible signals of efficacy

171 were found with respect to small improvements in anxiety and psychological quality of life from
172 baseline to 6-month follow-up. The clinical effectiveness of ACT adapted for plwMND was confirmed
173 in a recent RCT (Gould et al., 2024). This reported between-group differences in favour of ACT plus
174 usual care vs. usual care alone for quality of life and depression at 6-and 9-months post-
175 randomisation, psychological inflexibility at 9-months and brief health status at 6-months. Again, high
176 session attendance and satisfaction rates suggested the intervention was acceptable to plwMND.
177 However, uncertainty remains regarding plwMND's qualitative experiences of ACT given the
178 quantitative focus of the RCT.
179
180 As part of the earlier uncontrolled feasibility study (Gould et al., 2023), qualitative interviews with
181 plwMND who had received the intervention and therapists who had delivered it were conducted to
182 further assess the acceptability of ACT for plwMND. These interviews aimed to explore: i) the
183 acceptability of ACT for plwMND (including barriers to and facilitators of engagement in and delivery
184 of ACT); ii) perceived benefits from receiving ACT; and iii) how ACT could be refined in order to increase
185 its acceptability to this population. Qualitative findings from the perspective of plwMND who had
186 received the intervention and therapists who had delivered it are reported here. To the authors'
187 knowledge, this is the first study to qualitatively report on the acceptability of ACT for plwMND.
188

189 **Materials and methods**

190 This study reports on qualitative data from a pre-registered, uncontrolled study that examined the
191 feasibility and acceptability of ACT adapted for plwMND (ISRCTN Registry: ISRCTN12655391). The
192 Standards for Reporting Qualitative Research checklist (O'Brien et al., 2014) and the template for
193 intervention description and replication (TIDieR) checklist (Hoffmann et al., 2014) are provided in
194 Supplementary Files 1-2 to support transparent reporting.
195
196

197 **Design**

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

202

203 **Participants in qualitative interviews**

204 PlwMND were aged 18 years and over, and had a diagnosis of definite, laboratory-supported probable
205 or probable familial or sporadic ALS (which is diagnostically synonymous with MND (Al-Chalabi et al.,
206 2016)) using the World Federation of Neurology's El Escorial criteria (Brooks et al., 2000). PlwMND
207 were excluded if they: i) were lacking capacity to provide fully informed consent (either written,
208 verbally or via the use of a communication aid); ii) had insufficient understanding of English to enable
209 engagement in ACT or complete questionnaires; iii) had a clinical diagnosis of dementia; iv) required
210 gastrostomy feeding or non-invasive ventilation (i.e., were at stage 4 of King's clinical staging (Roche
211 et al., 2012)); v) were currently receiving psychological therapy or were unwilling to refrain from
212 psychological therapy during the receipt of ACT; vi) required treatment for severe psychiatric disorder
213 or were expressing suicidal ideation with active plans/suicidal behaviours and intent; or vii) had other
214 medical factors that could compromise full study participation.

215

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

219

220 **Recruitment**

221 Recruitment of plwMND to the uncontrolled feasibility study is described in Gould et al. (2023).
222 Recruitment of plwMND and therapists to this qualitative study via convenience sampling was as

223 follows: With the exception of those who withdrew from the feasibility study and so could not be
224 invited to participate in interviews, plwMND who participated in the feasibility study were approached
225 by local site staff or therapists and invited to participate in qualitative interviews. Those who gave
226 consent for contact were then approached by one of two researchers (KW or CR) via phone or email.
227 Therapists who delivered ACT within the feasibility study were also invited to participate and were
228 approached by KW or CR. All participants provided fully informed written consent to participate or
229 verbal consent/consent via the use of a communication aid, verified by an independent witness, for
230 those who could not provide written consent.
231
232 **Intervention**
233 PlwMND received up to eight sessions of ACT that had been tailored to the specific physical,
234 communication, cognitive and psychological needs of plwMND in accordance with previous qualitative
235 findings (Weeks et al., 2019). A brief summary of how ACT was adapted for the needs of plwMND is
236 listed in Table 1. Sessions were delivered on a one-to-one basis, for up to one hour each, in the
237 clinic/home or via video call, and were supplemented by audio recordings of ACT exercises. Sessions
238 were mostly weekly, extending to fortnightly and then monthly for the last two sessions to facilitate
239 a graded ending. An outline of each of the sessions is provided in Table 2. With the consent of the
240 person with MND, caregivers were invited to attend the assessment session and sessions examining
241 committed action. Usual multidisciplinary care was provided in addition to ACT.
242
243 [Insert Table 1 about here.]
244
245 All sessions, apart from the first and last, adopted the following structure: i) present moment
246 awareness exercise; ii) brief ratings of open, aware and engaged processes; iii) assessment of suicidal
247 ideation; iv) discussion of the previous session and home practice; v) introduction to a key ACT
248 process, together with associated experiential exercises and metaphors and home practice tasks (see

249 Table 2); and vi) session summary and home practice task. Although each session broadly focused on
250 a specific ACT process, therapists were encouraged to bring other ACT processes into each session.
251 The order in which ACT processes were focused on was chosen by the therapist, according to each
252 person's individualised ACT case conceptualisation. Therapists could modify the pace of the session,
253 as necessary, and were provided with a choice of a range of metaphors and exercises that could be
254 delivered in each session to suit individual needs and preferences. Intervention delivery was
255 supported by the use of a therapist manual detailing session outlines, metaphors and experiential
256 exercises, together with a client workbook, that could be used flexibly in order to address individual
257 ACT case conceptualisations, needs and preferences.
258
259 [Insert Table 2 about here.]
260
261 Qualified clinical psychologists, counselling psychologists and CBT therapists, who had been delivering
262 psychotherapy interventions for a minimum of one year post-qualification, were involved in
263 intervention delivery. All study therapists completed a four-day training course in ACT for plwMND
264 prior to delivering the intervention (irrespective of previous training or experience). Training included:
265 i) information about MND, common psychological issues in MND, and working with plwMND; ii) the
266 ACT model, metaphors and experiential exercises that address each of the ACT core processes, ACT
267 assessment and case conceptualisation, and flexibly application of ACT core processes; and iii) how to
268 adapt ACT for plwMND. Therapists were offered weekly group supervision via telephone by two
269 clinical psychologists and a psychiatrist with five or more years' experience of ACT. Therapists were
270 encouraged to attend these sessions on at least a fortnightly basis. All therapy sessions were audio
271 recorded using encrypted digital voice recorders. Ten percent of sessions were randomly chosen to
272 be assessed for treatment fidelity using the ACT Treatment Integrity Coding Manual (Plumb &
273 Vilardaga, 2010) by two independent ACT therapists. Further details about the intervention and
274 assessment of treatment fidelity are available in Gould et al. (2023).

275

276 **Data Collection**

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

286

287 [Insert Figure 1 about here.]

288

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

301 interviews were audio recorded, transcribed verbatim using a third-party transcription service, and
302 checked for accuracy and anonymised by CR or KW.
303

304 **Data Analysis**

305 CR independently reviewed all interviews and VF independently reviewed seven of them, and through
306 discussion, developed an initial thematic framework (Gale et al., 2013; Ritchie et al., 2014) around *a*
307 *priori* themes, such as the acceptability of ACT for plwMND, that also included emergent themes and
308 subthemes from the data. CR subsequently applied this framework, indexing instances of themes,
309 across all interviews. NVivo 12 was used to manage data and conduct thematic analyses using the
310 Framework Method (Gale et al., 2013). This approach was chosen for two reasons: i) due to the applied
311 focus on questions of acceptability and feasibility; and ii) as this approach facilitates comparison of
312 patients' and therapists' perspectives. CR then reviewed the range and diversity of data extracts within
313 each theme and subtheme. At this stage, data from the interviews with plwMND and therapists were
314 compared and contrasted, moving from surface meanings of the data to more analytic properties, to
315 unite the thematic framework. The process of interpretation was supervised by VL, who reviewed all
316 coding and theme descriptions, and RG, who reviewed theme descriptions. Further details about the
317 analysis process are outlined in Supplementary File 6.
318

319 **Trustworthiness**

320 Multiple methods were used to enhance the trustworthiness of the findings. These included keeping
321 field notes to help contextualise and interpret the data and using the topic guide flexibly to follow
322 participants' concerns. Multiple coding and supervision meetings were used to support reflexivity and
323 help identify and examine alternative interpretations of the data. Additionally, the thematic
324 framework was sense checked at multiple stages of the analysis with our Patient and Caregiver
325 Advisory Group, who had lived experience of living with or being affected by MND.
326

327 **Reflexive statement**

328 Our interpretivist approach acknowledges that researcher influence inevitably shapes the processes
329 of knowledge production. The interviewers (CR and KW) were white British females. Both had an MSc,
330 had completed training in qualitative research prior to conducting interviews, and had experience of
331 working with people with dysarthria. VF was a white British female, and had completed training in
332 qualitative research prior to data analysis as part of her MSc course. They were supervised by an
333 experienced qualitative researcher (VL, white British female, PhD) and a clinical academic with some
334 qualitative research training and experience (RG, white British female, PhD, DClinPsy). Only RG had in-
335 depth knowledge and experience of ACT.
336
337 CR and KW had built a relationship with some plwMND and all therapists prior to the interviews
338 through engagement in the feasibility study. RG had established prior relationships with therapists
339 through the provision of training and supervision in the feasibility study, while VF and VL had no prior
340 or ongoing relationships with plwMND or therapists. CR and VF were not involved in earlier phases of
341 the feasibility study and so were able to conduct interviews and initial data-driven analyses with a
342 relative independence from expectations of therapy. KW was involved in earlier phases of the
343 feasibility study, but only conducted three interviews and was not involved in data analysis. To
344 mitigate the risk of a positive bias in plwMND and therapists' reporting, the importance of sharing
345 both positive and negative experiences of intervention receipt or delivery was emphasised to all
346 participants prior to and during the conduct of interviews.
347
348 Increasing engagement with plwMND and therapists throughout the analysis period enhanced CR's
349 understanding of the nuances of MND and of individual variations in experiences. This, in turn,
350 enabled better contextualisation of the data and resulted in subsequent recoding into later themes.
351 Since increasing engagement with plwMND and therapists may have served to increase CR's
352 expectations of therapy, she frequently re-engaged with transcribed interviews to ensure that

353 analyses remained rooted in the data. As RG's possible allegiance to ACT may have influenced
354 interpretation of data, she was only involved in the theme development stages. Participants were not
355 given information about the researchers' personal goals or reasons for conducting the research.
356
357 **Ethical statement**
358 This study has been conducted in accordance with the principles stated in the Declaration of Helsinki.
359 Ethical approval was granted by the London–Dulwich Research Ethics Committee (REC reference
360 number: 18/LO/0227). All participants provided fully informed consent to participate in the study.
361
362 **Results**
363 Figure 1 shows the recruitment flow of participants in the study. Table 3 displays the demographic
364 and clinical characteristics of 14 plwMND who completed interviews. The average age of plwMND was
365 59.6 years (SD 12.4, range 31-73 years), with all self-identifying as White/White British (n=14/14) and
366 just over half self-identifying as male (n=8/14). Participants reported being most commonly diagnosed
367 with the ALS variant of MND (n=10/14).
368
369 [Insert Table 3 about here.]
370
371 The demographic and professional characteristics of 11 therapists who completed interviews are
372 shown in Table 4. Therapists were primarily female (n=10/11) and had been qualified for an average
373 of 7.8 years (SD 4.1, range 3-17 years). All therapists were qualified as clinical psychologists (n=11/11),
374 and the majority were employed as clinical psychologists at varying levels of seniority (n=8/11).
375
376 [Insert Table 4 about here.]
377
378

Qualitative findings

Four overarching 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. Though 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.

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)

405

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

409

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

413

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

419

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

423

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

430

431 Therapists also suggested that ACT is preferential over other psychological therapies such as
432 traditional cognitive behavioural therapy or problem focussed therapy as it does not focus on trying
433 to eliminate difficult internal experiences or problems.
434
435 *"I think for me there's something about ACT that just feels a little bit more… It's probably not entirely*
436 *accurate, but it feels less self-blaming or less that you should get rid of things. It feels a little bit more*
437 *realistic in the sense that this is a really difficult diagnosis and you are going to feel difficult emotions*
438 *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*
439 *life that's still meaningful. For me that feels a little bit more realistic and takes a lot of pressure off*
440 *people." (T1, F)*

441

442 A few therapists commented on how the timing of therapy and where it fits in a person's journey with
443 MND (e.g., with respect to adjustment to the diagnosis) needs to be carefully considered. For example,
444 it was suggested that if ACT is offered too close to diagnosis then denial/avoidance may impede
445 engagement in therapy. All but one person with MND said that they would recommend ACT for those
446 living with the condition.
447
448 *"I think there probably needs to be some thought about the timing of the therapy and where it fits with*
449 *somebody's journey with MND. I don't really know what the answer to that is, but I think people's*
450 *experience of the therapy and how they use it can be very different, depending on how early on they*
451 *are in terms of receiving their diagnosis and how physically affected they are." (T9, F)*
452
453 **ii) Better understanding of ACT exercises than overall ACT philosophy**
454 PlwMND reported variability in their understanding of the concepts and rationale of ACT.
455 Understanding was facilitated by congruence with personal philosophy or by personal experiences
456 such as profession. Barriers to understanding included the use of technical language and ambiguity in

457 the aims of ACT. PlwMND often reported better understanding of specific ACT exercises rather than
458 the overall philosophy of ACT. However, the ability to verbally describe ACT concepts was not
459 necessary for reported positive experiences.

460

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

463

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

466

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

470

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

474

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

478

479 **iii) The importance of a variety of ACT exercises to meet varied needs and preferences**
480 There was variability in the degree to which plwMND connected with and/or were able to implement
481 ACT exercises (see Supplementary File 5 for a description of these) in their daily lives. For example,

482 some plwMND connected with the mindfulness principle behind a present-moment awareness
483 exercise, the Centering exercise, while others appreciated it as a chance to relax, and some reported
484 they did not 'get it' and subsequently did not find it useful. Others identified the 'Leaves on a stream'
485 exercise and the 'Labels' exercise as the easiest to engage with and apply to their daily lives. Therapists
486 additionally commented on the usefulness of focusing on values in the sessions. Some plwMND
487 reported that certain metaphors (such as the 'house and furniture' and 'passengers on the bus'
488 metaphors) resonated with them and helped them to reflect on their experiences.

489

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

494

495 *"And the other aspect was the labelling, having labels. It was quite a practical exercise and visualising*
496 *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*
497 *another aspect." (P4, age 67, F)*

498

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

501

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

505

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

509

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

513

514 **Theme 2: The value of therapy outweighing the challenges**

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

520

521 **i) Positive experiences despite varied expectations**

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

529

530 ***"****I didn't really have any expectations because I had no idea at all what it was going to be." (P1, age*
531 *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)

578 PlwMND often associated a lack of perceived benefits or changes with a lower perceived need for
579 therapy at the outset. Some plwMND remarked that therapeutic benefits were contingent on the
580 effort and time put in with respect to home practice completion and session engagement.
581
582 *"I think that you've got to be pretty open-minded. You've got to be prepared to work quite hard, I think,*
583 *but if you are able to do that and see the wood for the trees, you'll come out of it with something." (P7,*
584 *age 68, M)*
585
586 **iii) The importance of the therapeutic relationship**
587 PlwMND emphasised the importance of having 1:1 time with a professional who had some knowledge
588 of MND (which was similarly echoed by one therapist), who was able to tailor the content and pace of
589 the sessions according to their needs and explain complicated concepts. They also valued being able
590 to talk openly to their therapists and feeling listened to, which positively contributed to the overall
591 therapeutic experience. Therapists valued the quality of the therapeutic relationship (e.g., the ability
592 to develop a good therapeutic rapport with the participant) and suggested that this facilitated the
593 person with MND's engagement in ACT.
594
595 *"It's not often you get the chance to speak to a professional for a full hour – and I sometimes went over*
596 *the hour – and open up your heart and mind. So I think that's a very positive thing for people in my*
597 *position." (P4, age 67, F)*

598

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

603

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

606

607 **iv) Therapy as emotionally challenging**

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

612

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

614

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

617

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

622

623 **v) The challenge of discussing sensitive topics**

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

627

628 *"Well it was just that particular statement at the beginning of every week that I said [suicide]. That*
629 *was the only thing really that I felt was invasive." (P4, age 67, F)*
630

631 *"I don't think there was anything that they found unacceptable, no. I think, and if you were around*
632 *asking about suicidal or self-harm, it wasn't that they were offended by that, but they just felt like it*
633 *was irrelevant and almost I could see a roll of the eyes and the head again." (T5, F)*
634

635 *"I can't say that there's a lot to be concerned about there. We talked about intimacy a bit, which is a*
636 *sensitive subject. But it was helpful to talk about it. Some people might not feel comfortable with that".*
637 *(P6, age 70, M)*
638

639 **Theme 3: Relevance to the individual**

640 The next theme was 'relevance to the individual', referring to factors that stemmed from individual
641 preferences and experiences. Four subthemes were identified: i) congruence with personal
642 philosophy or beliefs; ii) perceived need for therapy; iii) impact of previous experiences of therapy;
643 and iv) personal resonance and continued practice beyond therapy.
644

645 **i) Congruence with personal philosophy or beliefs**

646 Many plwMND alluded to a high congruency between the perceived principles of ACT and their own
647 personal philosophy or beliefs; contributing to an enhanced understanding and experience of ACT.
648

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

652

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

657

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

660

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

666

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

670

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

673

674 **ii) Perceived need for therapy**

675 Therapists noted that some plwMND with a lower perceived need for psychological intervention (for
676 example, those who were taking part due to their desire to “help out with research”) were less inclined

677 or willing to engage with therapy on a personal level. Other therapists noted that a lower perceived
678 need for therapy at the start of the sessions did not necessarily stop some plwMND from benefitting
679 from ACT.
680
681 *"I think working with him was quite rewarding because even though he came into it thinking he didn't*
682 *really need this kind of support, I think he and his wife both got a lot from it." (T4, F)*
683
684 **iii) Impact of previous experiences of therapy**
685 Therapists noted that previous experiences of other therapies impacted on engagement with ACT. For
686 example, previous experiences in relation to cognitive restructuring (i.e., thought challenging) were
687 incongruent with ACT principles and could act as a barrier to understanding of ACT concepts and hence
688 treatment outcome. A few plwMND commented on how their previous experiences of other therapies
689 impacted on their expectations of ACT, with ACT typically surpassing their expectations.
690
691 *"The only thing that I did notice is that he is someone who's had quite a lot of therapy in the past and*
692 *so he did veer towards thought challenging quite a lot. He's obviously had quite a bit of CBT. So it is*
693 *understandable that he would return to that way of problem solving. So I had to keep bringing him*
694 *back to the idea of acceptance and willingness, rather than trying to get rid of the thoughts." (T6, F)*
695
696 *"I think that notion of accepting the difficult stuff. She'd had previous experience of hypnosis and she*
697 *was quite into complimentary therapies. And I think she came into the therapy heavily invested in the*
698 *idea that these things can be taken away and, as I say, I don't think she fully accepted that sometimes*
699 *we just have to sit with the difficult things and find a space for them. It wasn't a problem for her*
700 *ultimately because what she was doing was broadly working and she did take on board the new*
701 *methods. But I think that was the most challenging part for her." (T2, M)*

702

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

708

709 **iv) Personal resonance and continued practice beyond therapy**

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

713

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

716

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

720

721 **Theme 4: Involving others**

722 The final theme identified was 'involving others', which considered the wider social network affected
723 by MND. It comprised two subthemes: i) the needs of others; and ii) support from others.

724

725 **i) The needs of others**

726 For a few plwMND, it was important to recognise the role of family, particularly the impact of MND
727 on family members and the importance of including them in therapy. The impact of MND on the family

728 was also recognised by a few therapists. One person with MND felt that family members should be
729 offered their own individual therapy.
730
731 *"Because at the end of the day, my thoughts are my family are actually going to end up suffering far*
732 *more than I'm suffering because they have to live after I'm not here. So their pain is continuing after*
733 *I'm not here. So my thoughts were that my family members surely would have benefitted from being*
734 *part of the therapy as well." (P10, age 51, M)*
735
736 *"His wife came as well and I think that was quite beneficial in a sense that you know motor neuron*
737 *disease has effect on the person but also has a real knock on effect for the whole family and extended*
738 *family as well." (T7, F)*
739
740 *"But just about the immediate family, that was something that I did wonder about because I did think*
741 *there should have been some mention about how your spouse or your family are coping with it as well.*
742 *And possibly anything one could do to discuss it with them as well and perhaps have some talking*
743 *therapy for them. It's just a thought." (P1, age 68, F)*
744
745 **ii) Support from others**
746 Therapists thought that involving family could be beneficial in facilitating therapeutic engagement,
747 particularly with respect to supporting the completion of home practice and attending sessions.
748
749 *"And also because her husband, who is a carer, attended that whole session, they were saying that it*
750 *was helpful for them to have time to discuss and work on the home practice together because it helped*
751 *them to start thinking about the future and not avoiding to think about what might happen in the*
752 *future. So, I think it's not just her, but also her carer said that he found it very helpful." (T8, F)*

753

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

757

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

760

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

767

768 **Discussion**

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

774

775 Findings demonstrated that plwMND and therapists perceived ACT to be an appropriate psychological
776 intervention for plwMND, providing support for previous recommendations for this population
777 (Pearlman & Thorsteinsson, 2019; Weeks et al., 2019). Both therapists and plwMND considered the

778 potential utility of ACT in coping with future disease progression as crucial to its value, supporting the
779 perceived acceptability of ACT across the disease course. These findings are consistent with previous
780 reports of the acceptability of ACT for people with life-limiting illnesses and neurological conditions,
781 including advanced cancer and multiple sclerosis (Giovannetti et al., 2020; Hulbert-Williams et al.,
782 2021). They are also in line with qualitative feedback showing that mindfulness-based interventions
783 are acceptable for those with neurodegenerative diseases of the motor system, including MND
784 (Marconi et al., 2016), Parkinson's disease (Bogosian et al., 2022) and premanifest Huntington's
785 disease (Eccles et al., 2021). This latter point is pertinent given that mindfulness or present-moment
786 awareness is one of the hypothesised core processes within ACT. Taken together, current and previous
787 studies support the suitability of 'third wave' psychological approaches, such as ACT and mindfulness-
788 based interventions, for those with neurodegenerative diseases of the motor system.
789
790 It has been previously suggested that perceived changes resulting from psychological therapy are
791 mediated by factors such as whether the therapy made sense to the individual and whether
792 therapeutic strategies and perspectives were personally resonant (Brooks et al., 2021). Themes and
793 subthemes identified in the current study are partially consistent with this. For example, our findings
794 showed that plwMND did not have to have a cognitive or verbal understanding of ACT concepts or
795 philosophy to experience beneficial effects, but those who described a personal resonance with or an
796 experiential understanding of ACT exercises reported more positive outcomes. This is consistent with
797 ACT's theoretical underpinnings (Hayes et al., 2012), which note that one can act with psychological
798 flexibility without being able to verbally explain the process, theory, or philosophy, and instead
799 emphasises an experiential understanding of ACT. That is, people do not need to be able to make
800 verbal or cognitive sense of ACT (i.e., they do not need to “get it”) in order to benefit from it. This
801 suggests that helping plwMND to develop a willingness to engage openly with therapy and gain an
802 experiential understanding of ACT exercises and principles, even if it does not make sense to them, is
803 important.

804

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

815

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

828

829 Although previous research has shown that higher expectations of therapy are associated with better
830 outcomes (Constantino et al., 2011), most plwMND reported neutral initial expectations of therapy,
831 and yet still reported a positive experience of ACT. For some, expectations of therapy varied across
832 the course of therapy, as has been reported by others (Brooks et al., 2021). Some plwMND described
833 how ACT required more work and committed input than anticipated; an observation that is not unique
834 to ACT, but which applies to experiences of psychological therapy in general (Brooks et al., 2021).
835 PlwMND who engaged actively and with personal investment reported the greatest changes, including
836 adoption of exercises and changes to one's outlook and perceptions of coping, consistent with
837 previous findings (Bendelin et al., 2020). The fact that all plwMND reported an altruistic motivation
838 for engaging in ACT as part of the feasibility study, rather than a perceived 'need' for psychological
839 therapy, may have influenced personal investment in therapy. Alternatively, it may be that those who
840 did not perceive a need for therapy (e.g., due to fewer adjustment issues) may have experienced fewer
841 opportunities to implement therapeutic techniques in their daily lives. This may also have contributed
842 to some people's reflections that ACT would be particularly helpful for those who they perceived as
843 coping less well with MND than they were.
844
845 Therapists having knowledge and prior experience of MND has been previously identified as an
846 important prerequisite for psychological therapy for this population (Rabbitte et al., 2015; Weeks et
847 al., 2019), as this can help to provide a 'safe space' for emotional exploration (Rabbitte et al., 2015).
848 Therapists being knowledgeable in MND was similarly highly valued by plwMND in the current study
849 and considered to positively contribute to the therapeutic experience. This emphasises the
850 importance of ACT, and more broadly psychological therapies, being delivered to plwMND by those
851 with specialist MND knowledge (such as those embedded within MND multidisciplinary teams) rather
852 than those based in generic mental health services.
853

854 A sense of personal relevance or congruence between ACT principles and an individual's personal
855 philosophy contributed to the experience of ACT in the current study. Some plwMND described a
856 feeling of 'resonance' or a natural engagement with ACT exercises, facilitated by their personal
857 philosophy or beliefs. Others felt that their existing 'positive' outlook resulted in limited additional
858 benefits from ACT, potentially reflecting a misunderstanding of ACT principles. PlwMND attributed the
859 flexibility of ACT, which could be tailored to the individual by therapists, to the therapy's success. This
860 is important to note given that: i) others have highlighted that the complexity and progression of MND
861 necessitates flexibility in therapy (Rabbitte et al., 2015; Weeks et al., 2019); and ii) previous findings
862 have shown that the lack of tailoring diminishes the perceived value of therapy for recipients (Brooks
863 et al., 2021).
864
865 Finally, although therapists and some plwMND felt that involving family in therapy could be beneficial
866 for all parties, some plwMND valued 1:1 sessions and the 'freedom' that came with speaking to a
867 stranger. This supports previous recommendations to consider both the person with MND's social
868 network in therapy (Harris et al., 2018) and their preferences with respect to involving others in
869 therapy (Weeks et al., 2019). One person with MND highlighted the need for family members to be
870 offered their own psychological therapy. There is currently little guidance as to what this should be,
871 due to the lack of high quality research in this area (Cafarella et al., 2022). ACT offers promise as a
872 psychological intervention suitable for caregivers of plwMND, in addition to plwMND, given that it has
873 been found to be acceptable and feasible in caregivers of people living with dementia (Kishita et al.,
874 2022). However, reports of a low adherence rate, coupled with no effects of treatment on primary or
875 secondary outcomes, in an RCT of a blended ACT-based intervention vs. waiting list in caregivers of
876 plwMND (De Wit et al., 2020) suggests that any future research should carefully consider how to
877 optimise intervention engagement in this population prior to assessing effectiveness.
878
879

880 **Clinical implications**

881 Key implications of the qualitative findings with respect to optimising the delivery of ACT to plwMND
882 are shown in Table 5. ACT for plwMND should accommodate the nature of the disease and individual
883 characteristics to support expectations and experiential understanding of ACT. The rationale for ACT
884 should be introduced early on and reiterated throughout therapy, and this should be tailored to
885 recognise varied motivations to engage in therapy, expectations of therapy and personal philosophies.
886 Some consideration should be given to whom ACT should be offered to (e.g., those for whom
887 treatment of emotional distress and/or adjustment issues is the aim vs. those for whom prevention
888 of such issues is the aim), and when ACT should be offered in the disease course (e.g., immediately
889 post-diagnosis vs. six months after diagnosis). It is important to recognise that a cognitive or verbal
890 understanding of ACT principles is not necessary to achieve benefits. However, non-technical
891 terminology and the use of concrete exercises and metaphors may facilitate an experiential
892 understanding of these. Therapy should also include a willingness to openly explore sensitive or
893 emotive topics such as suicide and sexual intimacy. Therapist prerequisites include having knowledge
894 of MND and how to tailor ACT exercises and metaphors to individual needs and preferences. Involving
895 family members may facilitate engagement in ACT for some plwMND.
896
897 [Insert Table 5 about here.]
898
899 **Research implications**

900 It has been previously argued that ACT may be particularly beneficial for plwMND (Weeks et al., 2019).
901 An uncontrolled feasibility study showed that ACT adapted for the specific needs of plwMND appears
902 to be feasible to deliver and acceptable to this population, as indicated by good session attendance
903 and high satisfaction rates, respectively (Gould et al., 2023). The clinical effectiveness of ACT adapted
904 for plwMND for maintaining or improving quality of life was confirmed in a recent RCT (Gould et al.,
905 2024). High session attendance and satisfaction rates again suggested the intervention was acceptable

906 to plwMND. The qualitative results reported here build on previous evidence in providing further
907 support for the acceptability of ACT adapted for plwMND. Future research should investigate
908 moderators of treatment outcome in ACT for plwMND, including factors that have been identified
909 here such as expectations and perceived personal relevance of ACT, as well as perceived need for
910 therapy, as a means of identifying who might benefit the most from this type of therapy.
911
912 **Strengths and limitations**
913 To the authors' knowledge, this is the first study to explore the qualitative experiences and reflections
914 of plwMND receiving ACT and therapists delivering ACT to this population, addressing a recognised
915 shortfall of therapy-specific and qualitative research in MND (Gould et al., 2015; Harris et al., 2018;
916 Pagnini, 2013). Furthermore, insights from therapists served to contextualise reports from plwMND
917 and enhance interpretation of the data.
918
919 However, there are several limitations of this study. First, the findings cannot be generalised to
920 plwMND in more advanced stages of the disease (i.e., those with a need for gastrostomy or non-
921 invasive ventilation) or those with comorbid dementia due to our inclusion criteria. They can also not
922 be generalised to those using augmentative and alternative communication devices as no plwMND
923 reported using these in our study. Similarly, results cannot be generalised to a broader demographic
924 population of plwMND and therapists given that the majority of plwMND self-identified as
925 White/White British and only one therapist self-identified as male. Future studies should ascertain the
926 acceptability of ACT in broader and more diverse populations of plwMND.
927
928 Second, it is important to recognise that our findings may be subject to a positivity bias. While
929 interviews were conducted by a researcher who was independent from the person with MND's clinical
930 team, some participants may have been unwilling to report negative experiences of therapy to the
931 researcher, as noted by others (Holding et al., 2016). This may be particularly applicable to plwMND

932 and therapists who had built a relationship with the researchers through participation in the feasibility
933 study. Furthermore, it was not possible to explore experiences of ACT in those who withdrew from
934 the feasibility study (due to withdrawing consent to be contacted) or declined an interview. Interviews
935 with plwMND and therapists may have also been subject to an allegiance bias as a result of positive
936 experiences of receiving and delivering ACT. Additionally, the degree of engagement in the
937 intervention may have been influenced by high levels of motivation given that high levels of
938 motivation to engage in research have been reported in previous studies of plwMND (Beswick et al.,
939 2024). Consequently, future studies should seek to examine the acceptability of ACT in those who
940 disengage from it, as well as engagement in ACT in real world or naturalistic settings.
941
942 **Conclusions**
943 PlwMND and therapists reported positive overall experiences of receiving and delivering ACT.
944 Variations in experiences of ACT may be attributable to numerous factors, including differences in the
945 perceived need for therapy, expectations about ACT and the perceived personal relevance of ACT.
946 Future research and clinical practice should aim to recognise and account for these individual factors
947 to optimise the delivery of ACT to plwMND.
948
949

950 **Key practice points**

951 • Adapted ACT was perceived as being acceptable to both plwMND receiving it and therapists
952 delivering it.
953 • Value was particularly placed on the potential utility of ACT for helping plwMND to cope with
954 future disease progression.
955 • Therapists having knowledge of: i) MND; ii) a range of ACT exercises and metaphors; and iii) how
956 to tailor ACT exercises and metaphors to suit individual needs and preferences was seen as crucial
957 to the experience of ACT.
958 • Accounting for key implications of the qualitative findings may further improve the acceptability
959 of ACT to plwMND.
960

961 **Further reading**

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List of Supplementary Files

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Supplementary File 2. The template for intervention description and replication (TIDieR) checklist.

Supplementary File 3. Topic guides for semi-structured interviews with people living with MND and therapists.

Supplementary File 4. Diagram for introducing ACT to plwMND.

Supplementary File 5. Description of ACT exercises in the intervention.

Supplementary File 6. Detailed outline of steps in the qualitative analysis.

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 et al., 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 et al., 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 & 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.

Notes: ACT = Acceptance and Commitment Therapy, MND = motor neuron disease, plwMND = people living with MND.

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 & 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

Note: [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 Supplementary 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 Centering exercise, and each session explored small steps that could be taken in service of the person's values.

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
No. with a self-reported mental health diagnosis	14 (0, 0%)	1 (7%)
No. prescribed psychotropic medication	13 (1, 7%)	3 (21%)
Fluoxetine		1 (7%)
Citalopram		1 (7%)
Amitriptyline		1 (7%)

Notes: 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%)

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	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.

Theme	Sub-theme	Key implication(s)
the challenges	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.

Theme	Sub-theme	Key implication(s)
	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.

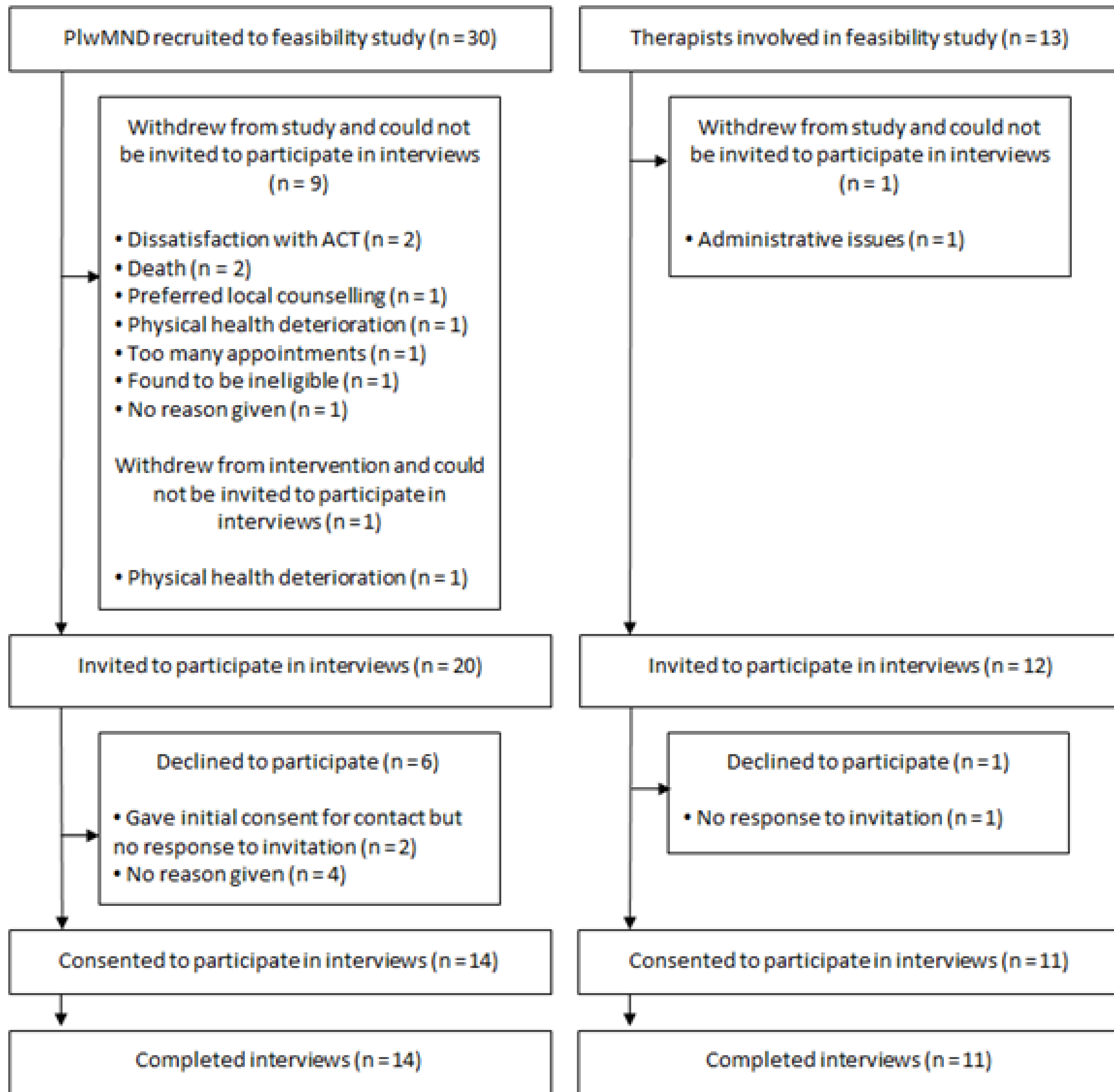


Figure 1. Recruitment flow of participants.

Supplementary File 1. Standards for reporting qualitative research (SRQR) checklist.

Title and abstract	**Page no.**
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4-6
Purpose or research question - Purpose of the study and specific objectives or questions	6
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	7, 11
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	12-13

Context - Setting/site and salient contextual factors; rationale**	8
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	7
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	13
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	10-11
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	10
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7, 14, Tables 3-4
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	11
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	11-12

Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	12
Results/findings	
Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	14-30
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	14-30
Discussion	
Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	30-36
Limitations - Trustworthiness and limitations of findings	36-37
Other	
Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Title page
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Title page

Supplementary File 2: The template for intervention description and replication (TIDieR) checklist.

No.	Item	Where located (page no.)
	BRIEF NAME	
1.	Provide the name or a phrase that describes the intervention.	1
	WHY	
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	4-5
	WHAT	
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL).	9
4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	8-9
	WHO PROVIDED	
5.	For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.	9

	HOW	
6.	Describe the modes of delivery (e.g., face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	8
	WHERE	
7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	8
	WHEN and HOW MUCH	
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	8
	TAILORING	
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	8-9
	MODIFICATIONS	
10.	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	N/A
	HOW WELL	
11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	9-10

12.	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	Described in Gould et al. (2023)

Supplementary File 3. Initial and final topic guides for semi-structured interviews with people living with MND and therapists.

Initial topic guide for people living with MND

Experiences of receiving Acceptance and Commitment Therapy

1. How would you describe your experience of the intervention?
2. How did you find the intervention?
    a. What was helpful?
    b. What was not helpful?
3. Have you experienced any changes as a result of receiving the intervention?
    a. Everyday life
    b. Relationships with your partner, relatives or friends
    c. Occupational or leisure activities
4. How understandable was the intervention?
    a. What was understandable?
    b. What was confusing?
5. How acceptable was the intervention?
    a. What was acceptable?
    b. What was not acceptable?
6. What difficulties did you experience during the intervention?
7. What did you think about the practical aspects of the intervention?
    a. Number of sessions
    b. Frequency of sessions
    a. Settings
8. What helped you engage with the intervention?

9. What barriers were there to engaging with the intervention?

Changes to Acceptance and Commitment Therapy

10. What would you like to change about the intervention?
11. Do you have any other comments about the intervention?

Other questions

12. Is there anything else you would like to add that we have not talked about?

<u>Final topic guide for people living with MND</u>

Experiences of receiving Acceptance and Commitment Therapy

1. How would you describe your experience of Acceptance and Commitment Therapy?
    a. *Prompts: Would you describe it as a positive or negative experience? Why?*
2. How helpful did you find Acceptance and Commitment Therapy?
    a. *Prompts: What was helpful or what did you most like about it?*
    b. *Prompts: What was not helpful or what didn't you like about it? Why?*
3. Have you experienced any changes as a result of receiving Acceptance and Commitment Therapy?
    a. *Prompts: Changes in how you think about things?*
    b. *Prompts: Changes in how you feel about life?*
    c. *Prompts: Changes in your day-to-day life?*
    d. *Prompts: Changes in your wellbeing or health?*
    e. *Prompts: Changes in your relationships with your partner, relatives or friends?*
    f. *Prompts: Changes in your leisure activities or hobbies?*
    g. *Prompts: Changes in your occupational or voluntary activities?*

4. How easy to understand was Acceptance and Commitment Therapy in terms of its philosophy and different elements?
    a. *Prompts: What made sense? What was confusing? Why?*
5. To what extent do you think Acceptance and Commitment Therapy met your needs?
    a. *Prompts: Did it meet your expectations of therapy? Why/why not?*
    b. *Prompts: Did you get all that you had hoped to get out of therapy? Why/why not?*
    c. *Prompts: To what extent do you think it was suitable for who you are?*
    d. *Prompts: What was acceptable? What was not acceptable? Why?*
6. What difficulties did you experience participating in Acceptance and Commitment Therapy?
    a. *Prompts: Difficulties attending the sessions? Understanding the sessions? Completing the home practice?*
7. What did you think about the practical aspects of how the therapy was delivered?
    a. *Prompts: Number of sessions?*
    b. *Prompts: How frequently you met?*
    c. *Prompts: Setting in which therapy was delivered (e.g. in person or via videoconferencing such as Skype)?*
8. What helped you feel involved in Acceptance and Commitment Therapy?
    a. *Prompts: Relationship with therapist?*
    b. *Prompts: Setting?*
    c. *Prompts: Type of therapy?*
9. Was there anything that made it difficult to get involved in Acceptance and Commitment Therapy?
    a. *Prompts: Having to travel to clinic? Not enough time? Physical health problems? Other hospital appointments? Too much effort? Lacking energy? Type of therapy? Mode of delivery (e.g. via Skype)?*

10. Would you recommend Acceptance and Commitment Therapy to a friend who was experiencing similar difficulties to you?
    a. *Prompts: Why (if yes)? Why not (if no)?*

Changes to Acceptance and Commitment Therapy

11. What would you like to change about Acceptance and Commitment Therapy?
    a. *Prompts: Specific aspects of therapy? A different type of therapy?*
12. What would you like to change about the practical aspects of Acceptance and Commitment Therapy?
    a. *Prompts: Different location? More/fewer sessions? Different frequency of sessions (e.g. more than once a week or less than once a week such as fortnightly)?*

Other questions

13. Do you have any other comments about Acceptance and Commitment Therapy?
    a. *Prompts: Is there anything else you would like to add that we have not talked about?*

Initial topic guide for therapists:

Experiences of delivering Acceptance and Commitment Therapy

1. How would you describe your experience of delivering the intervention?
2. How did you find delivering the intervention?
    a. What was helpful?
    b. What was not helpful?
3. How understandable was the intervention?
    a. What was understandable?
    b. What was confusing?

13. How acceptable was the intervention?

    a. What was acceptable?

    c. What was not acceptable?

4. How easy was it to deliver the intervention?

    a. What was easy?

    b. What was difficult?

5. What difficulties did you experience during delivering the intervention?

6. What did you think about the practical aspects of the intervention?

    a. Number of sessions

    b. Frequency of sessions

    c. Settings

7. What helped engagement with the intervention?

8. What barriers were there to engagement with the intervention?

Changes to Acceptance and Commitment Therapy

9. What would you like to change about the intervention?

10. How could engagement with the intervention be optimised?

11. Do you have any other comments about the intervention?

Other questions

12. Is there anything else you would like to add that we have not talked about?

<u>Final topic guide for therapists:</u>

Experiences of delivering Acceptance and Commitment Therapy

1. How would you describe your experience of delivering the intervention?
    a. *Prompts: Positive experience? Negative experience? Why?*
2. What did you like or not like about delivering the intervention?
    a. *Prompts: What did you like about it? What did you find helpful?*
    b. *Prompts: What didn't you like about it? What didn't you find helpful? Why?*
    c. *Prompts: Were there some aspects that worked better than others? Aspects that didn't work?*
3. How easy was it to deliver the intervention?
    a. *Prompts: Did you have any anxieties/concerns about delivering ACT at the outset?*
    b. *Prompts: What was easy? What was difficult?*
4. How understandable was the intervention to the people you were working with?
    a. *Prompts: What was understandable? What was confusing? Why?*
5. How suitable do you think your clients found the intervention?
    a. *Prompts: What seemed to be acceptable? What was less acceptable? Why?*
6. What changes did you see in the people that you worked with over the course of the intervention?
    a. *Prompts: Emotional? Behavioural? Cognitive?*
7. What difficulties did you experience during the delivery of the intervention?
    a. *Prompts: Clients not attending sessions? Clients or yourself not understanding the intervention? Clients not completing the home practice?*
8. What did you think about the practical aspects of delivering the intervention?
    a. *Prompts: Number of sessions? Frequency of sessions? Setting in which therapy was delivered (e.g. in person or via videoconferencing such as Skype)?*
9. What helped clients engage with the intervention?
    a. *Prompts: Relationship with therapist? Setting? Type of therapy?*
10. What barriers were there to clients engaging with the intervention?

a. *Prompts: Clients having to travel to clinic? Clients not having enough time? Clients' physical health problems? Clients' hospital appointments? Too much effort for clients? Clients lacking energy? Type of therapy? Mode of delivery (e.g. via Skype)?*

11. Would you recommend the intervention to other therapists for this client group?
    a. *Prompts: Why (if yes)? Why not (if no)?*
12. How did the intervention meet your expectations as a therapist?
    a. *Prompts: Did you achieve all that you had hoped to achieve as a therapist with the intervention? Why/why not?*
13. Have you experienced any changes in your professional work as a result of delivering the intervention?
    a. *Prompts: Changes in your clinical practice?*
14. How did you find the experience of delivering ACT within the context of a research study?
    a. *Prompts: Did this present any difficulties?*
    b. *Prompts: Did it help in any way?*
    c. *Prompts: Anything that you think could have been done differently?*
15. What helped you deliver ACT to this client group?
    a. *Prompts: Supervision?*
    b. *Prompts: Past experience?*
    c. *Prompts: Peer support?*
    d. *Prompts: Training?*

Changes to Acceptance and Commitment Therapy

16. What would you like to change about the intervention?
    a. *Prompts: Specific aspects of therapy? A different type of therapy?*

    Prompts: What would you like to change about the manual?
17. How could engagement with the intervention be optimised?

    a. *Prompts: Provide support in between sessions? Involve more people?*

18. What would you like to change about the practical aspects of the intervention?

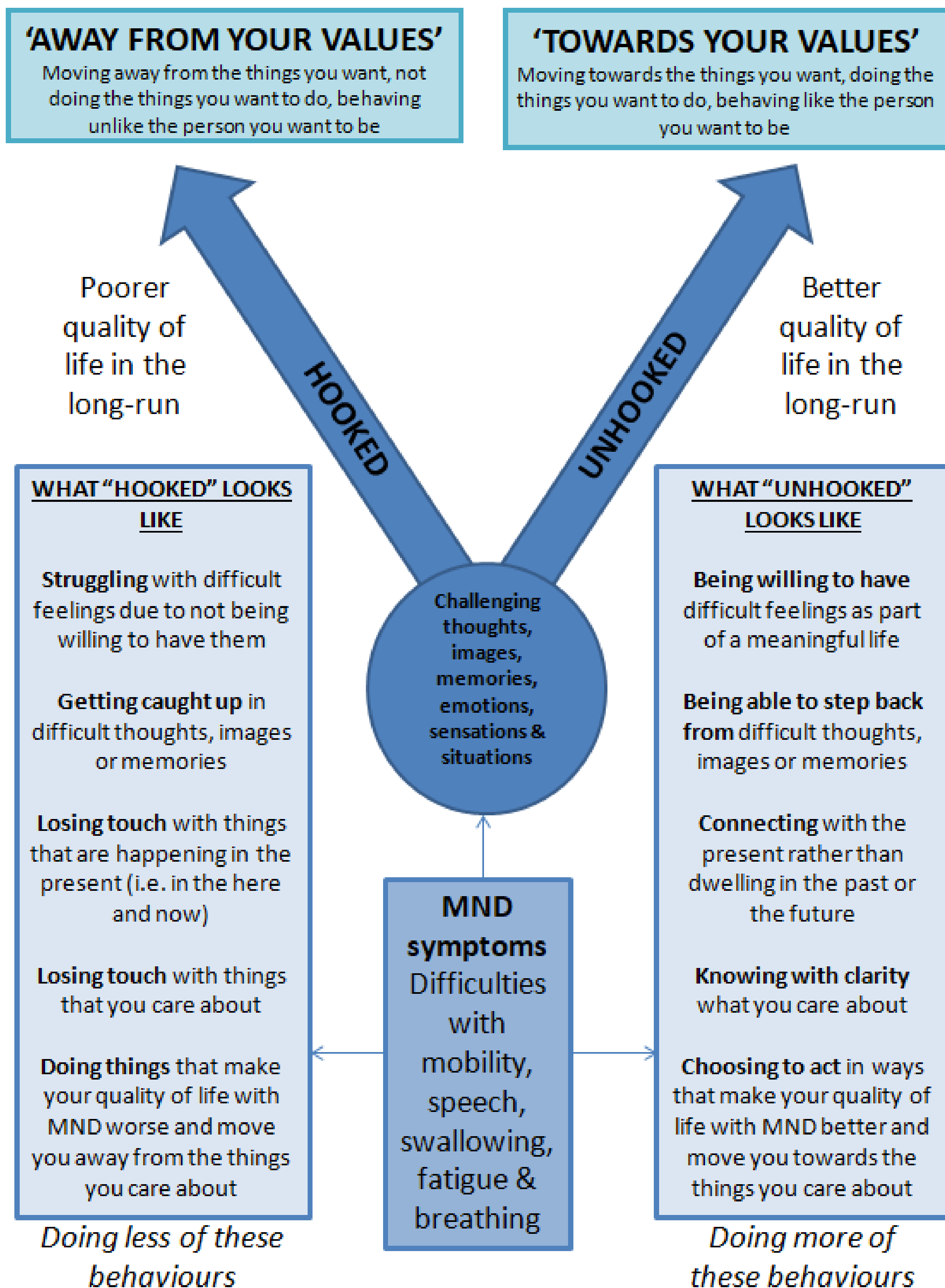
    a. *Prompts: Different location? More/fewer sessions? Different frequency of sessions?*

Other questions

19. Do you have any other comments about the intervention?

    a. *Prompts: Is there anything else you would like to add that we have not talked about?*

Supplementary File 4. Diagram for introducing ACT to plwMND.



Note: Adapted from Harris (2017) and Rose et al. (2018).

References:

Harris R. Choice Point 2.0. 2017. Available at: https://www.actmindfully.com.au/wp-content/uploads/2018/06/Choice_Point_2.0_A_Brief_Overview_-_Russ_Harris_April_2017.pdf

Rose MR, Norton S, Vari C, Edwards V, McCracken L, Graham CD, et al. Acceptance and commitment therapy for muscle disease (ACTMus): Protocol for a two-arm randomised controlled trial of a brief guided self-help ACT programme for improving quality of life in people with muscle diseases. BMJ Open 2018;8:e022083.

Supplementary File 5. Description of ACT exercises in the intervention.

ACT process/exercise	**Brief description**
Acceptance/willingness	Making space for or opening up to your internal experiences (i.e., thoughts, images, memories, emotions, sensations) rather than trying to control, change, avoid or get rid of them.
Passengers on the bus	An exercise in which you explore alternatives to struggling with or giving into your internal experiences, by simply acknowledging them and allowing them along for the ride.
Accepting all of you	A present-moment awareness exercise for opening up to internal experiences and bringing kindness and self-compassion to yourself.
Physicalising exercise	An exercise in which you imagine what physical properties an internal experience has, as a means of opening up to difficult experience.
Willingness exercise	A present-moment awareness exercise for exploring willingness to open up to internal experiences.
Your kind friend	A present-moment awareness exercise for bringing acceptance, kindness and self-compassion to yourself.
Defusion	Stepping back from your thoughts, images and memories rather than buying into them or treating them as if they are the literal truth.
"I notice I'm having the thought…"	An exercise in which you explore the difference between buying into a thought and noticing that you are having a thought.
Singing or saying a thought	An exercise in which you explore changing the context in which a thought is experienced by singing or saying it in different ways.
Writing a thought	An exercise in which you explore changing the context in which a thought is experienced by writing it in different colours or styles.

"Milk, milk, milk"	An exercise in which you explore changing the context in which a thought is experienced by repeating it over and over again.
Imagine a thought on a computer screen	An exercise in which you explore changing the context in which a thought is experienced by imagining changing the properties of a thought on a computer screen.
Leaves on a stream	A present-moment awareness exercise for simply watching your thoughts coming and going, without engaging in them or without trying to push them away.
Contact with the present moment	Bringing present-moment awareness to your internal experiences in the here-and-now rather than being caught up in the past or future as conceptualised by your mind.
Centering exercise	An exercise for bringing present-moment awareness to your internal experiences, values and the actions taken in service of your values.
Notice 5 things	An exercise for bringing present-moment awareness to things you can see, hear and feel in your body.
Tracking your thoughts in time	An exercise for bringing awareness to where in time your mind lies and practicing staying more in the present moment.
Self-as-context	Seeing yourself as distinct from your internal experiences rather than seeing yourself as defined by them.
Labels exercise	An exercise that identifies the labels that you give yourself or other people give you, and explores seeing yourself as separate or distinct from these labels rather than defined by them.
House and furniture metaphor	An exercise that explores seeing yourself as separate or distinct from your internal experiences, just as the furniture in a house is separate from the house.

Very brief self-as-observer	A present-moment awareness exercise for practicing seeing yourself as separate or distinct from your internal experiences.
Connecting with the noticing you	A present-moment awareness exercise for practicing noticing that there is a safe, secure and stable place inside from which you can observe your changing internal experiences.
Values	Knowing what matters to you (i.e., what you care about and the type of person you want to be) rather than losing connection with this.
Lifetime achievement award, Values list, Values questions	Exercises designed to help you identify your values (i.e., the type of person you want to be or the personal qualities you want to bring to your life and the lives of others).
Life compass	An exercise designed to help you evaluate your progress in moving towards your values, and areas where this can be improved.
Committed action	Taking action to do what matters to you rather than doing nothing, acting on impulse or behaving in ways that pull you away from your valued directions.
Willingness and action plan	A goal planning exercise that identifies goals and actions in service of values, and incorporates selection, optimisation and compensation strategies for overcoming external barriers (e.g., physical limitations).
Small steps exercise	An exercise that identifies goals and actions in service of values, and the internal and external barriers that automatically show up.

Note: ACT exercises listed are those that therapists were able to choose from in the intervention to meet the varied physical, cognitive and communication needs of plwMND.

Supplementary File 6: Detailed outline of steps in the qualitative analysis.

1. Familiarisation with interviews through independent reading and re-reading of all transcripts by [researcher 1] and seven transcripts by [researcher 2].
2. Development of initial thematic framework (164 codes for plwMND and 214 codes for therapists) by [researcher 1] and [researcher 2]:
    a. Training days
    b. The manual
    c. Intervention methods
    d. Particular activities (therapist POV)
    e. Particular activities (patient POV)
    f. Managing patient expectations
    g. Dealing with clients who wouldn't normally be an NHS client for therapy due to 'coping'
    h. Practical challenges for patients
    i. Patients with communication difficulties (therapist POV)
    j. Homework (therapist POV)
    k. Involving friends and family
    l. Other admin
    m. Anxieties for therapists
    n. Other challenges for patients
    o. Timing of sessions
    p. Starting therapy - setting the scene beyond consent
    q. Rating scales
    r. Reported unacceptable by patients
    s. Engagement, barriers and facilitators reported by patients
3. Sense checking with Patient and Caregiver Advisory Group.

4. Coding of all transcripts using initial thematic framework.
5. Review of data extracts and refinement of the thematic framework (188 codes for plwMND and 249 codes for therapists):
    a. PlwMND:
        i. Intervention methods
        ii. Particular activities
        iii. Managing patient expectations
        iv. Participants' view of coping and relevance
        v. Practical challenges for patients
        vi. Homework
        vii. Involving friends and family
        viii. Other challenges for patients
        ix. Timing of sessions
        x. Starting therapy - setting the scene beyond consent
        xi. Rating scales
        xii. Acceptability/unacceptability
        xiii. Engagement, barriers and facilitators reported by patients
        xiv. RCT - the impact of randomisation
        xv. Perceived impact of therapy
        xvi. Suitability of ACT for MND
        xvii. Understanding
    b. Therapists:
        i. Training days
        ii. The manual
        iii. Intervention methods
        iv. Particular activities (therapist POV)

v. Particular activities (patient POV)
vi. Managing patient expectations
vii. Dealing with clients who wouldn’t normally be an NHS client for therapy due to ‘coping’
viii. Practical challenges for patients
ix. Patients with communication difficulties (therapist POV)
x. Homework
xi. Involving friends and family
xii. Other admin
xiii. Anxieties for therapists
xiv. Other challenges for patients
xv. Timing of sessions
xvi. Starting therapy - setting the scene beyond consent
xvii. Rating scales
xviii. Reported unacceptable by patients
xix. Engagement, barriers and facilitators reported by patients

6. Review of the range and diversity of data extracts within each theme and subtheme.
7. Codes (197 for plwMND and 232 for therapists) organised according to key themes and underlying dimensions and then compared and contrasted to create initial themes across both datasets:
    a. Feasibility*
        i. Practical flexibility
            1. Location, method and scheduling
            2. Therapy delivery schedule
        ii. Accessibility of resources
            1. Online resources
            2. Practical challenges with physical resources

        3. Admin and organisation

b. Acceptability

    i. ACT as appropriate in MND

        1. ACT philosophy and MND

        2. ACT vs other therapies

    ii. Acceptability

    iii. Understanding

c. The therapeutic experience

    i. Expectations

    ii. Impact

    iii. Experiencing ACT sessions

        1. Emotions

        2. Exercises

    iv. The therapeutic relationship

d. Individuality

    i. Involving family and friends

    ii. Relevance to the participant

        1. Congruency with personal philosophy

        2. Perceived need and coping

e. Engaging in research*

    i. Research and the participant

        1. Motivation and mood symptoms

        2. RCT

        3. Research processes (i.e. outcome measures, RCT)

    ii. Being a therapist in COMMEND

        1. New therapy, new cohort

2. Being a researcher

8. Development of final themes after further sense checking:

    a. An appropriate tool to navigate the disease course

        i. ACT seen as appropriate given the disease prognosis

        ii. Better understanding of ACT exercises than overall ACT philosophy

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

    b. The value of therapy outweighing the challenges

        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

        v. The challenge of discussing sensitive topics

    c. Relevance to the individual

        i. Congruence with personal philosophy or beliefs

        ii. Perceived need for therapy

        iii. Impact of previous experiences of therapy

        iv. Personal resonance and continued practice beyond therapy

    d. Involving others

        i. The needs of others

        ii. Support from others

Notes: *'Feasibility' and 'Engaging in research' were not included as final themes in this paper as they were either not relevant given the aims of the paper (e.g. 'Engaging in research' focused on future research) or not specific to ACT (e.g. 'Feasibility' focused more broadly on generic pragmatics of delivering psychological therapies to plwMND).