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Experiences of psychological interventions in neurodegenerative diseases: a systematic review and thematic synthesis

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ABSTRACT

Background: Psychological interventions for managing emotional distress in neurodegenerative diseases are needed, but progressive worsening of symptoms and increasing disability might pose difficulties with engagement. We aimed to synthesise the experiences of engaging with and using psychological interventions in neurodegenerative diseases and identify relevant barriers and facilitators. *Methods:* Systematic searches were conducted in six electronic databases and results were screened. We included qualitative and mixed methods studies reporting patient or caregivers' views or experiences of psychological interventions. Qualitative data were extracted and thematically synthesised. *Results:* 34 papers were included, covering a range of diseases and interventions. Engagement was facilitated by flexible intervention formats and tailoring to the specific needs of people with neurodegenerative diseases. Interventions were sometimes inaccessible or burdensome because of physical and cognitive symptoms, and the time and effort required for the intervention. Participants' levels of acceptance and readiness often differed and influenced engagement with the intervention. Across different interventions, participants experienced wide-ranging benefits including changes in insight, perspective, self-efficacy, emotions and relationships. *Conclusion:* Although people with neurodegenerative diseases and caregivers experience benefits from psychological interventions, burden-reducing adaptations and sensitive tailoring to the specific disease context is required to improve acceptability and engagement.

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KEYWORDS

Neurodegenerative disease; psychological intervention; psychosocial intervention; psychotherapy; thematic synthesis; qualitative evidence synthesis

Introduction

Neurodegenerative disease is an umbrella term for diseases that are characterised by progressive degeneration of the structure and function of the nervous system. Common neurodegenerative diseases include Alzheimer's disease, Parkinson's disease, Motor Neurone Disease/Amyotrophic Lateral Sclerosis (MND/ALS) and Huntington's disease. Each of these diseases manifest and progress differently. However, all neurodegenerative diseases have some common features – they are progressive, disabling, and are a major threat to survival (Cummings & Pillai, 2016). The psychological impact can also be similar across the diseases because of certain common changes (e.g., decreasing functional

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status, changes in social roles and experiencing multiple losses as the disease gets worse) (Ovaska-Stafford et al., 2021). People with neurodegenerative diseases experience significant psychological distress including anxiety and depression (Dale & van Duijn, 2015; Kurt et al., 2007; Reijnders et al., 2008; Thompson et al., 2012). Caregivers also experience burden, depression and anxiety (Aoun et al., 2013; Iavarone et al., 2014; Martínez-Martín et al., 2007) which is sometimes related to the disease severity and neuropsychiatric symptoms experienced by the person with the neurodegenerative condition (Allegrì et al., 2006; Martínez-Martín et al., 2007; Schrag et al., 2006; Tramonti et al., 2019). Psychological distress can occur early or late in the disease trajectory and can have a negative impact on the quality of life for both people with neurodegenerative diseases and caregivers (Baquero & Martín, 2015; Fischer et al., 2012).

Psychological interventions have the potential to help people with neurodegenerative diseases and caregivers reduce psychological distress and have a better quality of life. The evidence for the effectiveness of psychological interventions is mixed, especially across different neurodegenerative diseases. For example, there is some evidence to suggest that psychological interventions are effective for improving psychological well-being in Parkinson's disease and dementia (Orgeta et al., 2015; Zarotti, Eccles, et al., 2020). In other neurodegenerative diseases (e.g., MND/ALS and Huntington's Disease) the literature is sparse and the need for more research on interventions has been emphasised (Gould et al., 2015; Thomas et al., 2006; Zarotti, Dale, et al., 2020; Zarotti, Mayberry, et al., 2020). For caregiver interventions, there is more evidence for the effectiveness of psychological interventions for caregivers of people with dementia (Cheng et al., 2019; Liu et al., 2017; Selwood et al., 2007). In other diseases like Parkinson's disease, Huntington's disease and MND/ALS, there has been less research on interventions for caregivers' psychological support (Harris et al., 2018; Hempel et al., 2008). Psychological interventions may be of benefit for people with neurodegenerative diseases and caregivers, but currently evidence is limited or inconclusive.

Researchers and clinicians have identified specific barriers that can affect how patients and caregivers with neurodegenerative diseases might engage with psychological interventions. Approaches like Cognitive Behavioural Therapy (CBT) could be challenging because the progression of physical symptoms is generally irreversible and some negative cognitions about the situation are realistic rather than distorted (Cole & Vaughan, 2005; Hind et al., 2010). Similarly, with caregivers, the seemingly unchangeable nature of their situation may make some CBT therapeutic goals difficult to achieve (Fowler et al., 2021). Approaches like Acceptance and Commitment Therapy (ACT) have been proposed as more suitable and acceptable as they focus on accepting distress and finding new ways to carry out valued activities (Fowler et al., 2021; Graham et al., 2015).

The level of physical disability and cognitive impairment with neurodegenerative diseases may also affect engagement with psychological interventions. Physical disability can make accessing mental health interventions difficult because of issues with transportation (Dobkin et al., 2013; Marconi et al., 2016). Additionally, cognitive impairment is typical in Alzheimer's disease, but it can also present in Parkinson's disease, multiple sclerosis (MS) and MND/ALS. Cognitive changes can affect how people engage with therapy and interventions (Cole & Vaughan, 2005; Weeks et al., 2019). Caregivers typically spend several hours a day assisting the person with the neurodegenerative disease or organising care and this can leave little time for other activities (Galvin et al., 2018; Zhang et al., 2018).

Given ongoing uncertainty about the effectiveness of psychological approaches in many neurodegenerative conditions and the likelihood of significant health-related barriers to engagement, being open to understanding how people experience these interventions is vital. Qualitative research allows for the patient and caregivers' perspectives to be prioritised and explored in-depth and detail. Whilst qualitative studies of patient and caregivers' experiences of various psychological interventions for a range of neurodegenerative diseases have been published, this literature has not yet been synthesised. We, therefore, aimed to synthesise and review findings from qualitative research in order to obtain a detailed and comprehensive understanding of engagement and acceptability, identifying issues that are relevant to patients and caregivers with a range of

neurodegenerative conditions, therapeutic approaches and delivery modes. Bringing together these findings will offer important insights to guide those involved in planning, delivering and evaluating interventions for patients with neurodegenerative diseases and their caregivers and help drive the development of more acceptable, engaging and effective interventions.

Methods

We conducted a systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement (Sohrabi et al., 2021) and analysed data using a thematic synthesis (Thomas & Harden, 2008). The protocol was prospectively registered on PROSPERO (CRD42021223125). We followed the ENTREQ (enhanced transparency in reporting the synthesis of qualitative research) checklist to facilitate systematic reporting (Tong et al., 2012).

Search strategy

A systematic search was carried out in six electronic databases (MEDLINE, PsycINFO, CINAHL Plus, Web of Science, AMED and the Cochrane library). The searches were conducted in October 2020 and updated in October 2021. Search terms were developed from initial literature scoping, consultation with a specialist librarian, and were piloted to ensure relevant studies were being included. The search strategy combined terms relating to psychological interventions, neurodegenerative diseases, and qualitative or mixed methods research (see supplementary file 1 for search terms). Grey literature was also searched (OpenGrey and ProQuest), and references of included studies were hand-searched. No date limits were applied, and results were restricted to those published in English.

Table 1. Review inclusion and exclusion criteria.

Criteria	Inclusion	Exclusion
Population	Adults who have a neurodegenerative disease (Alzheimer's disease, Huntington's disease, Parkinson's disease, Motor neuron disease/ Amyotrophic lateral sclerosis, Multiple system atrophy, Multiple sclerosis) Both people who have neurodegenerative diseases and their family caregivers.	Children or young adults with neurodegenerative diseases Adults with acute, non-progressive neurological illness (e.g., stroke, brain injury) Mixed population of older adults, some with dementia or mild cognitive impairment and some without. Healthcare professional or researcher perspectives
Intervention	Psychotherapeutic or psychoeducational interventions aimed at managing the emotional impact of neurodegenerative diseases/aimed at reducing distress or improving psychological wellbeing. Interventions in any format or mode of delivery Evaluations of psychological support services that aim to improve emotional wellbeing (e.g., counselling service)	Interventions designed to improve management of physical symptoms cognitive impairments and behaviour difficulties. Multidisciplinary or multicomponent interventions that do not have a substantial psychotherapeutic or educational component about coping with stress and difficult emotions. Interventions that only provide social support, or that use creative therapies (e.g., art, dance, music) or adaptations to the environment.
Outcome	Experiences and views of using psychological interventions, reported from the patient and/or family caregiver perspective.	
Study design	Qualitative studies and mixed methods studies with a substantial qualitative component Qualitative data and reporting that includes adequate depth and detail of methods and findings to be able to interpret meaning about the experience of using psychological interventions.	Studies with quantitative data only Systematic and other literature reviews Open-ended questionnaire data, or brief researcher commentary on the acceptability and feasibility of interventions.
Types of publication	Primary research including peer-reviewed articles, theses and dissertations.	Commentaries, book chapters, editorials, clinical guidelines, or recommendations.

Inclusion and exclusion criteria

The detailed inclusion and exclusion criteria are shown in [Table 1](#). We sought to identify qualitative and mixed methods studies that had a substantial qualitative component that investigated patient and caregivers' experiences and views of using psychological interventions. We included neurodegenerative diseases such as Alzheimer's disease, Huntington's disease, Parkinson's disease, Motor neurone disease/Amyotrophic Lateral Sclerosis (MND/ALS), Multiple system atrophy, and multiple sclerosis (MS). We defined psychological interventions as interventions that had psychotherapeutic or psychoeducational content and where the focus/aim was to reduce emotional distress or improve wellbeing or coping skills.

Screening and selection

The search results were exported to EndNote and duplicates were removed. All titles and abstracts were screened for eligibility by one author (CP). 15% were screened independently by a second reviewer (CM) and discrepancies were resolved through discussion and consensus. All full-text screening was conducted by CP and CM independently, any conflicts were resolved through discussion, involving a third reviewer (LD) where necessary.

Data extraction and quality appraisal

The data was extracted into a table and included data about study characteristics, participants and the interventions. All qualitative data (participant quotes and interpretations of findings) from the results and discussion sections were imported to NVivo for analysis and synthesis.

All included studies were assessed for quality using the Critical Appraisal Skills Programme (CASP) qualitative research checklist (Campbell et al., 2012; Mays & Pope, 2000). The CASP is a well-recognised checklist for assessing quality in qualitative studies and has been previously used to assess qualitative studies which seek to understand experiences of interventions in other disease groups (Cox et al., 2017; Maund et al., 2019). Details of the quality assessment for each included study can be found in Supplementary file 2. We did not exclude low-quality studies but took quality ratings into account when describing and interpreting the confidence in the findings.

Analysis and synthesis

Data were analysed using a thematic synthesis (Thomas & Harden, 2008). We selected this method because it allowed us to stay close to the original context of the primary studies, and draw conclusions about participants' experiences across a heterogeneous group of neurodegenerative diseases and intervention types through developing analytic themes which go beyond the interpretations presented in the primary studies. Extracted data was managed and coded using NVivo software. An inductive line-by-line coding of the data was carried out for each primary study. The list of 'free' codes for each study was then systematically compared, similar codes were combined and grouped into descriptive themes, paying attention to and recording whether the theme was represented in interventions with patients, caregivers or both groups. The wider review team then discussed the descriptive themes in relation to the review question. The descriptive themes were compared with each other and diagrams were used to identify specific issues with engagement and acceptability. Abstract or analytic themes that went beyond the content of original studies were developed, the descriptive themes were examined in light of these analytic themes, and changes to the analytic themes were made iteratively. This process was repeated until the analytic themes sufficiently captured the descriptive themes and answered the review question. The analytic themes were further refined during the process of writing up the results.

We used the GRADE CERQual approach (Lewin et al., 2018) as a systematic and transparent way to evaluate confidence in our principal review findings (i.e., our analytic themes). GRADE CERQual considers four components: methodological limitations, coherence, adequacy of data and relevance; ratings were assigned through discussions between CP and LD.

Results

Figure 1 shows the studies identified and included and excluded at different stages of the screening and selection process. Thirty-four papers met the inclusion criteria and were included in the review. The different neurodegenerative diseases included were dementia ($n = 19$), MS ($n = 9$), Parkinson's disease ($n = 3$), MND/ALS ($n = 2$) and Huntington's disease ($n = 1$). Thirteen papers included people with neurodegenerative diseases as participants, 14 included caregivers as participants and 7 papers included both people with neurodegenerative diseases and caregivers together. The different types of interventions covered were mindfulness ($n = 15$), ACT ($n = 6$), multicomponent psychoeducational interventions ($n = 6$), CBT ($n = 5$), dignity therapy ($n = 1$) and compassion-focussed therapy ($n = 1$). Further details about the included papers can be found in Table 2.

Assessment of quality and confidence in review findings

Individual study quality ratings can be found in Supplementary file 2. Overall, studies were of high quality, with papers scoring 7 or higher on a scale from 1 to 10 on the CASP checklist. Studies tended

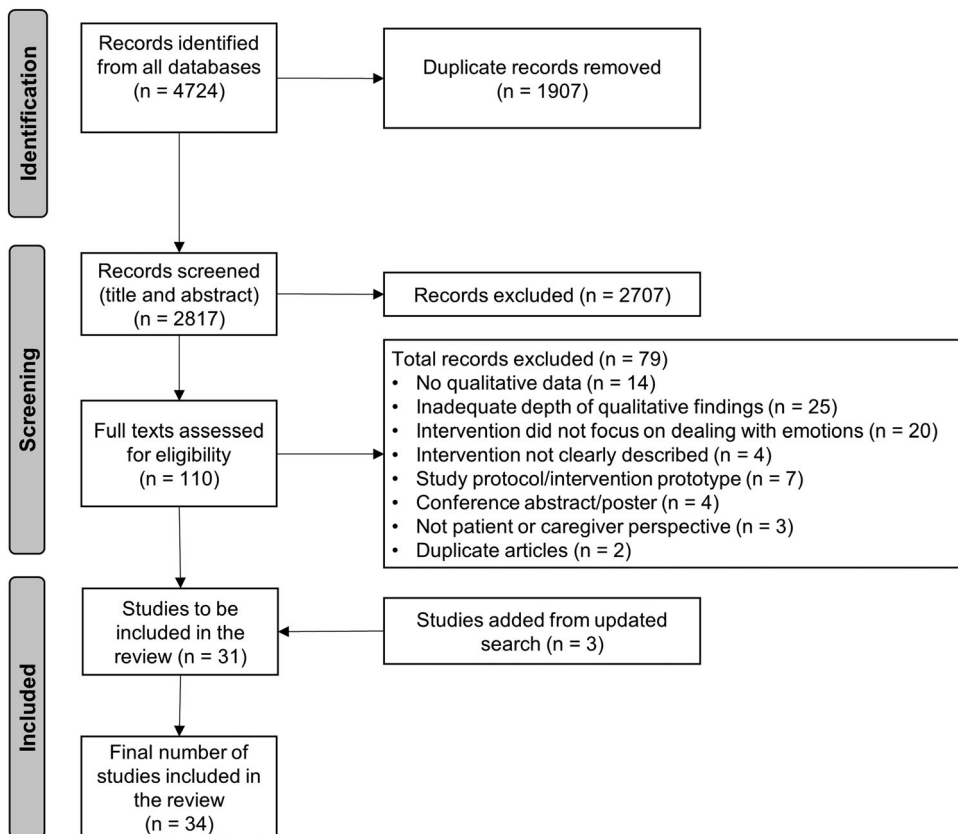


Figure 1. PRISMA diagram.

Table 2. Summary table of included studies.

Author, year, location	Disease	Participants and (sample size)	Data collection and analysis	Intervention details (intervention type, delivery, duration)
Adams (2018), UK	Dementia	Patients and caregivers (6–3 patients and 3 caregivers)	Semi-structured interviews Thematic analysis and constant comparative method	Mindfulness-based stress reduction Group, face-to-face 8 sessions, 2 h each
Berk et al. (2019), Netherlands	Dementia	Patients and caregivers (12 – 6 patients and 6 caregivers)	Semi-structured interviews Deductive content analysis	Mindfulness-based stress reduction Group, face-to-face 8 sessions, 2.5 h each
Bogosian et al. (2016), UK	Multiple sclerosis	Patients (15)	Semi-structured interviews Thematic analysis	Mindfulness-based stress reduction Group, video conference 8 sessions, 1 h each
Bogosian et al. (2021), UK	Parkinson's disease	Patients (26)	Interviews Thematic analysis	Mindfulness-based cognitive therapy Group, video conference 8 sessions, 1 h each
Craig et al. (2018), UK	Dementia	Patients and caregivers (5)	Semi-structured interviews Thematic analysis	Compassion focused therapy Group, face-to-face 10 sessions, 1 h each
de Wit et al. (2019), Netherlands	MND/ALS	Caregivers (23)	Semi-structured interviews Thematic analysis	Psychoeducation based on ACT Individual, blended (face-to-face, online and telephone) 6 online modules completed in own time, 1 face-to-face & 1 phone session
Dennison et al. (2013), UK	Multiple sclerosis	Patients (30)	In-depth interviews Thematic analysis with some grounded analytic techniques	Cognitive behaviour therapy Individual, blended (face-to-face and telephone) 8 sessions, 1 h each
Douglas et al. (2021), UK	Dementia	Patients and caregivers (14–8 patients and 6 caregivers)	Semi-structured interviews Thematic analysis	Mindfulness-based cognitive therapy Group, face-to-face 8 sessions, 1.5 h each
Eccles et al. (2020), UK	Huntington's disease	Patients (11)	Interviews Framework analysis	Mindfulness-based cognitive therapy Group, face-to-face 8 sessions, 2 h each
Fitzpatrick et al. (2010), UK	Parkinson's disease	Patients (12)	Semi-structured interviews Interpretative Phenomenological Analysis	Mindfulness-based cognitive therapy Group, face-to-face 8 sessions, 2.5 h each
Giovannetti et al. (2020), Italy	Multiple sclerosis	Patients (30)	Interviews Content analysis	Acceptance and Commitment therapy Group, face-to-face 8 sessions, 2.5 h each
Glueckauf et al. (2012), USA	Dementia	Caregivers (10)	Semi-structured interviews Open coding procedure and categorisation into themes	Cognitive Behavioural therapy Group and individual, blended (face-to-face and telephone) 12 sessions, 1 h each
Gottberg et al. (2016), Sweden	Multiple sclerosis	Patients (12)	Semi-structured interviews Content analysis	Cognitive Behavioural Therapy Individual, face-to-face 15–20 sessions, 50 mins each
Han et al. (2021), USA	Dementia	Caregivers (7)	Semi-structured interviews Interpretive Phenomenological Analysis	Acceptance and Commitment therapy Individual, video conference 10 sessions, 1 h each
Hind et al. (2010), UK	Multiple sclerosis	Patients (17)	In-depth interviews Framework analysis	Cognitive Behavioural Therapy Individual, computer/online 5–8 weekly sessions, completed in own time
Hoppes et al. (2012), USA	Dementia	Caregivers (11)	Semi-structured interviews thematic analysis with	Mindfulness-based stress reduction

(Continued)

Table 2. Continued.

Author, year, location	Disease	Participants and (sample size)	Data collection and analysis	Intervention details (intervention type, delivery, duration)
Johannessen et al. (2015), Norway	Dementia	Caregivers (20)	grounded theory open coding Interviews Content analysis	Group, face-to-face 4 sessions, 1 h each Multicomponent psychoeducational Group and individual, face-to-face 15 sessions (2 half day seminars, 5 h long counselling sessions and 8 group meetings)
Johnston et al. (2016), UK	Dementia	Both patients and caregivers (27)	Interviews and focus group Framework analysis	Dignity therapy Individual, face-to-face Not mentioned, time spent to undertake interview with person and then edit the dignity document.
Kazmer et al. (2018), USA	Dementia	Caregivers (7)	Semi-structured interviews Open coding, axial coding, categorisation via concept mapping	Cognitive Behavioural therapy and spiritual counselling Individual, face-to-face 12 sessions, 1 h each
Larochette et al. (2020), France	Dementia	Caregivers (23)	Semi-structured interviews and questionnaire Thematic analysis	Acceptance and commitment therapy Individual, face-to-face 7 sessions, 90 mins each
Lavoie et al. (2005), Canada	Dementia	Caregivers (30)	Semi-structured interviews Content analysis	Psychoeducation Group, face-to-face 15 sessions, 2 h each
Marconi et al. (2016), Italy	MND/ALS	Both patients and caregivers (44–26 patients, 18 caregivers)	Semi-structured interviews Grounded theory approach to analysis	Mindfulness-based stress reduction Group, face-to-face 8 sessions, (duration not mentioned)
Martin et al. (2015), UK	Dementia	Patients (6)	Focus groups and interviews Thematic analysis	Psychoeducation Group, face-to-face 6 sessions, 2.5 h each
Nehrig and Chen (2019), USA	Dementia	Caregivers (15)	Semi-structured interviews Thematic analysis	Psychoeducation Individual, face-to-face 12 sessions, duration not mentioned
Nehrig, Gillooly, et al. (2019), USA	Dementia	Caregivers (14)	Semi-structured interviews Thematic analysis	Psychoeducation Individual, face-to-face 12 sessions, duration not mentioned
Nehrig, Shifrin, et al. (2019), USA	Dementia	Caregivers (22)	Semi-structured interviews Thematic analysis	Psychoeducation Individual, face-to-face 12 sessions, duration not mentioned
Pegler (2017), UK	Dementia	Caregivers (8)	Feedback surveys and focus group Framework analysis	Acceptance and commitment therapy Group, face-to-face 3 sessions, 2.5 h each
Potter et al. (2021), UK	Multiple sclerosis	Caregivers (7)	Semi-structured interviews Framework analysis	Acceptance and commitment therapy Individual, remote (self-help text and telephone) 8 sessions, duration not mentioned
Sessanna et al. (2021), USA	Multiple sclerosis	Patients (14)	Focus group Thematic analysis	Mindfulness based stress reduction Group, blended (face-to-face and online) 8 sessions, 1 h each
		Patients (33)		

(Continued)

Table 2. Continued.

Author, year, location	Disease	Participants and (sample size)	Data collection and analysis	Intervention details (intervention type, delivery, duration)
Simpson et al. (2018), UK	Multiple sclerosis		Semi-structured interviews Thematic analysis and framework approach	Mindfulness based stress reduction Group, face-to-face 8 sessions, duration not mentioned
Simpson et al. (2019), UK	Multiple sclerosis	Patients (33)	Semi-structured interviews Deductively using normalisation process theory constructs	Mindfulness based stress reduction Group, face-to-face 8 sessions, duration not mentioned
Swannell (2017), UK	Dementia	Both patients and caregivers (8–4 patients and 4 caregivers)	Semi-structured interviews Thematic analysis	Mindfulness based stress reduction Group, face-to-face 8 sessions, 1.5 h each
Tahsin et al. (2021), Canada	Dementia	Caregivers (6)	Interviews Thematic analysis	Mindfulness Group, face-to-face 1 session, 15 mins
Vandenberg et al. (2019), Australia	Parkinson's disease	Patients (16)	Semi-structured interviews Thematic analysis	Mindfulness based stress reduction Group, face-to-face 6 sessions, 2 h each

to be weaker on reporting the relationship between researchers and participants, and reporting data analysis methods sufficiently. Included studies scored well on clearly stating the aims of the research and appropriate use of qualitative methodology.

The GRADE CERQual evaluation found that in addition to the included studies being of high quality, a large number of studies contributed to the development of each analytic theme, the studies had rich data, and the themes were relevant across different diseases and intervention types (see Supplementary file 3). The evaluation process, therefore, concluded that there was high confidence in three analytic themes and moderate confidence in one analytic theme. Overall, we are confident that the review findings are a reasonable representation of the experiences of psychological interventions among people with neurodegenerative diseases and caregivers.

Themes

We developed four analytic themes; Figure 2 outlines the descriptive and analytic themes and the relationship between them. These themes were common for people with neurodegenerative diseases and caregivers. Where specific differences occur between these two participant groups, they are discussed within each theme.

Adequate levels of tailoring and flexibility

Engagement with psychological interventions was either facilitated or hindered by adequate intervention tailoring and flexibility. Disease-specific tailoring was often used to adapt the intervention content and activities to the specific disease or the specific needs of caregivers. People with neurodegenerative diseases and caregivers found disease-specific information and advice helpful (Adams, 2018; Bogosian et al., 2021; de Wit et al., 2019; Dennison et al., 2013; Eccles et al., 2020; Gottberg et al., 2016; Hind et al., 2010; Kazmer et al., 2018; Nehrig, Shifrin, et al., 2019; Simpson et al., 2018; Simpson et al., 2019) and discussed the importance of therapists or facilitators having disease-specific knowledge (Craig et al., 2018; de Wit et al., 2019; Dennison et al., 2013; Gottberg et al., 2016; Kazmer et al., 2018; Martin et al., 2015; Simpson et al., 2019). Caregivers also appreciated interventions that were targeted to their own unique needs and difficulties (de Wit et al., 2019; Larochette et al., 2020; Nehrig,

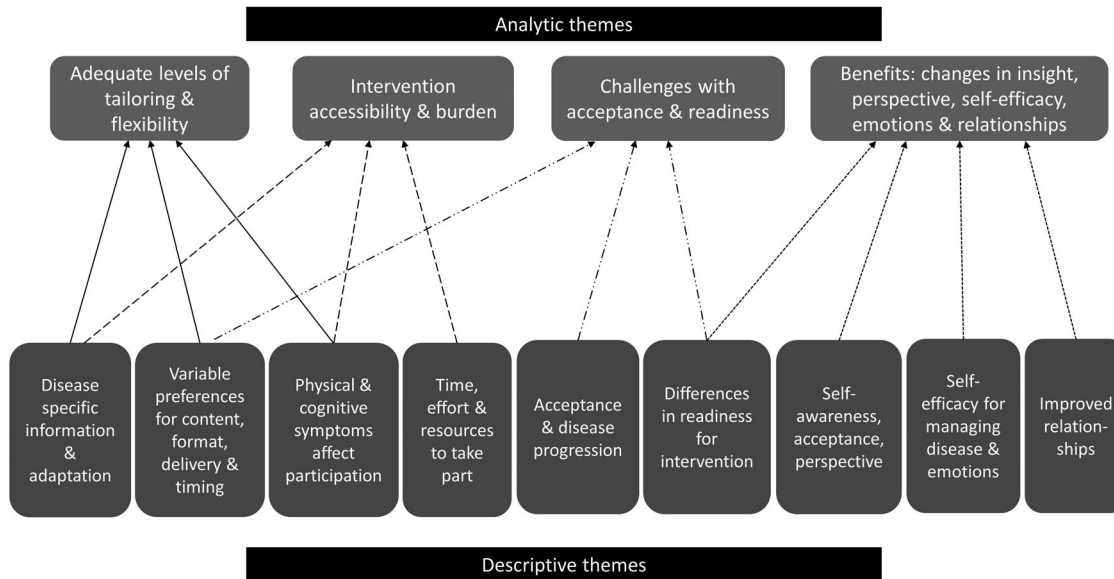


Figure 2. Analytic and descriptive themes.

Shifrin, et al., 2019) and appreciated the ability to choose intervention modules that were relevant to their situation (de Wit et al., 2019; Larochette et al., 2020).

I don't think you can have mixed abilities walking round and everybody happy ... I just felt the delivery needed to be a bit more sensitive to the needs of people with MS and MS is very different from chronic fatigue or any other thing like that.. it might have been better to have somebody who has actually been ill or not been well to have an input into the delivery on the course. [person with MS, mindfulness intervention (Simpson et al., 2019)]

People with the same neurodegenerative disease can have different physical and cognitive symptoms and consequently, intervention activities and delivery formats need to be adjusted. People with neurodegenerative diseases stressed the importance of adapting interventions so that they were user-friendly for people with varying levels of ability and cognition (Adams, 2018; Martin et al., 2015; Sessanna et al., 2021; Simpson et al., 2018; Simpson et al., 2019; Swannell, 2017) and also went a step further to adapt the activities to their own individual routines and circumstances (Adams, 2018; Berk et al., 2019; Eccles et al., 2020; Larochette et al., 2020; Martin et al., 2015; Swannell, 2017; Vandenberg et al., 2019).

Similarly, intervention formats and delivery methods need to be flexible to accommodate people with different symptoms and needs or levels of ability. This could be through ensuring flexibility in intervention duration. Some participants preferred shorter intervention durations (Berk et al., 2019; Giovannetti et al., 2020; Simpson et al., 2018; Simpson et al., 2019), whereas others wanted more time to enable learning, practising and group work (Berk et al., 2019; Bogosian et al., 2016; Bogosian et al., 2021; Craig et al., 2018; de Wit et al., 2019; Dennison et al., 2013; Eccles et al., 2020; Giovannetti et al., 2020; Larochette et al., 2020; Martin et al., 2015; Nehrig & Chen, 2019; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Pegler, 2017; Potter et al., 2021; Sessanna et al., 2021; Simpson et al., 2018; Simpson et al., 2019; Tahsin et al., 2021). Interventions also require some flexibility in terms of mode of delivery. Face-to-face options were valued because of the bond and rapport created between participants or between participants and therapists which made it easier to talk about difficult issues (de Wit et al., 2019; Dennison et al., 2013; Gottberg et al., 2016; Potter et al., 2021; Sessanna et al., 2021). However, face-to-face sessions were difficult if people had problems with mobility, transportation or had other conflicting commitments (Berk et al., 2019; Eccles et al., 2020; Gottberg et al., 2016; Marconi et al., 2016; Simpson et al., 2018). Accessing the intervention remotely (online or by telephone/at home) was convenient, easy to use, and could be completed at the individual's own pace (Bogosian et al., 2021; de Wit et al., 2019; Dennison et al., 2013; Hind et al., 2010; Johnston et al., 2016; Sessanna et al., 2021) but difficulties with concentration, technology and the lack of human interaction could make engagement challenging (de Wit et al., 2019; Dennison et al., 2013; Hind et al., 2010; Sessanna et al., 2021).

With MS you can become very isolated because of your disability ... So, I think when working with something that is a computer programme it makes you feel even more like you're not speaking to someone face to face. You don't get the empathy there. [person with MS, computerised CBT (Hind et al., 2010)]

Being at different disease stages could also impact intervention preferences. Group settings generally facilitated intervention engagement (Adams, 2018; Berk et al., 2019; Bogosian et al., 2021; Johannessen et al., 2015; Lavoie et al., 2005; Pegler, 2017; Swannell, 2017); however, some participants found it difficult to engage with the group if they were not similar to other participants in terms of symptoms or disease stage (Berk et al., 2019; Bogosian et al., 2016; de Wit et al., 2019; Eccles et al., 2020; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Johannessen et al., 2015; Lavoie et al., 2005; Simpson et al., 2018; Simpson et al., 2019). Some preferred the intervention early on in their disease trajectory (Adams, 2018; de Wit et al., 2019; Dennison et al., 2013; Johannessen et al., 2015; Nehrig, Gillooly, et al., 2019; Simpson et al., 2018), but others felt that the intervention was too early and they faced fewer problems that they needed help with (de Wit et al., 2019; Dennison et al., 2013; Gottberg et al., 2016; Hind et al., 2010; Pegler, 2017; Simpson et al., 2018).

I think the program came at a good time. That everything is still relatively new for you, and can put your own things into perspective and that you receive support. Otherwise, you will keep going in circles for too long. [caregiver for person with MND/ALS, ACT intervention (de Wit et al., 2019)]

Tailoring and flexibility are also needed because of variability in coping preferences and preferences for therapy. Some participants preferred practical and structured support because it was more focused and suited people who had a more pragmatic approach to coping (de Wit et al., 2019; Giovannetti et al., 2020; Gottberg et al., 2016; Johannessen et al., 2015; Kazmer et al., 2018; Lavoie et al., 2005; Martin et al., 2015; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019). Others preferred opportunities to connect with peers or a therapist, have open discussions, and access emotional support (Bogosian et al., 2016; de Wit et al., 2019; Dennison et al., 2013; Eccles et al., 2020; Johannessen et al., 2015; Nehrig & Chen, 2019; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019). There were also different preferences for working in patient-caregiver dyads and for including other family members in the intervention (Adams, 2018; Berk et al., 2019; Giovannetti et al., 2020; Johannessen et al., 2015; Johnston et al., 2016; Swannell, 2017).

Intervention accessibility and burden

Some psychological interventions or some components of the intervention were experienced as inaccessible or burdensome, and this could act as a barrier to engaging with the intervention. People with neurodegenerative diseases found it difficult to take part in and complete intervention activities because of physical and cognitive symptoms (Adams, 2018; Berk et al., 2019; Craig et al., 2018; Marconi et al., 2016; Martin et al., 2015; Sessanna et al., 2021; Swannell, 2017). Difficulties with cognition (in particular, concentration or memory difficulties) impacted their ability to sustain attention during the intervention, learn and practice new techniques/strategies (Adams, 2018; Berk et al., 2019; Craig et al., 2018; Douglas et al., 2021; Hind et al., 2010; Marconi et al., 2016; Martin et al., 2015; Swannell, 2017). Cognitive difficulties also made information processing difficult if information is too much or too technical (Adams, 2018; Berk et al., 2019; Martin et al., 2015); therefore, having adequate time and clear instructions when learning new activities was important (Douglas et al., 2021; Martin et al., 2015; Sessanna et al., 2021).

Participants discussed the impact cognitive decline had on being able to practice MBSR (Mindfulness-based stress reduction). This varied from remembering to practice, to being unable to hold on to, or understand, the concept of mindfulness. Some participants felt it improved their concentration, while others felt it was not beneficial for people with dementia. [study author, dementia, mindfulness intervention, (Swannell, 2017)]

Physical symptoms can also make participation in intervention activities difficult (Berk et al., 2019; Dennison et al., 2013; Eccles et al., 2020; Gottberg et al., 2016; Hind et al., 2010; Marconi et al., 2016; Martin et al., 2015; Simpson et al., 2018; Simpson et al., 2019). For example, mindfulness activities such as mindful movement or mindful walking could sometimes prove unhelpful and insensitive to the participants who had difficulties with mobility (Simpson et al., 2018; Simpson et al., 2019). Symptoms such as pain, weakness and fatigue made it difficult to sit for long periods of time, to write, hold a phone for a long period of time, or lift a heavy manual (Dennison et al., 2013; Hind et al., 2010; Simpson et al., 2018; Simpson et al., 2019). Those with mobility issues or difficulties with balance and fatigue found it difficult to get to face-to-face sessions, and were frustrated by the lack of disability-friendly facilities (Berk et al., 2019; Eccles et al., 2020; Gottberg et al., 2016; Marconi et al., 2016; Martin et al., 2015; Simpson et al., 2018; Simpson et al., 2019).

My brain just couldn't cope with it because it was so busy just trying not to fall over ... and of course sometimes there's no feeling in your feet ... so no, that was very challenging. [person with MS, mindfulness intervention, (Simpson et al., 2018)]

Additionally, the time and effort involved in taking part in a psychological intervention could sometimes be burdensome. Both caregivers and people with neurodegenerative diseases found it difficult to carve out time to participate due to other conflicting commitments and caring responsibilities

(Adams, 2018; Bogosian et al., 2021; de Wit et al., 2019; Douglas et al., 2021; Eccles et al., 2020; Hind et al., 2010; Pegler, 2017; Potter et al., 2021; Simpson et al., 2018; Simpson et al., 2019; Swannell, 2017). Interventions were sometimes viewed as effortful or demanding (Bogosian et al., 2016; Craig et al., 2018; Dennison et al., 2013; Gottberg et al., 2016; Hind et al., 2010; Nehrig, Shifrin, et al., 2019; Potter et al., 2021; Swannell, 2017). Activities such as thought restructuring, goal setting, or mindfulness, that brought up difficult emotions or thoughts about physical impairment/disability, were difficult and some felt they could even be detrimental (Bogosian et al., 2016; Dennison et al., 2013; Gottberg et al., 2016; Hind et al., 2010; Swannell, 2017).

The participants became aware that CBT is essentially a continuous process, with no pause between the sessions, but they also became aware that they did not always have enough time and energy in their everyday lives to focus on changing themselves. [study author, MS, CBT intervention, (Gottberg et al., 2016)]

Both patients and caregivers expressed that committed practice and time were required to apply what they had learned in the intervention to their own lives (Adams, 2018; Berk et al., 2019; Craig et al., 2018; Douglas et al., 2021; Giovannetti et al., 2020; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Simpson et al., 2018; Simpson et al., 2019; Swannell, 2017) and it was sometimes difficult to find the time and energy to practise intervention strategies (particularly completing homework) or to find time for self-care (Adams, 2018; Berk et al., 2019; de Wit et al., 2019; Douglas et al., 2021; Gottberg et al., 2016; Hind et al., 2010; Kazmer et al., 2018; Potter et al., 2021; Simpson et al., 2018; Swannell, 2017). Having support from work or family gave people more time and facilitated their participation in interventions (Douglas et al., 2021; Gottberg et al., 2016; Nehrig, Shifrin, et al., 2019).

Participants requested further flexibility to adapt the spacing of the reading they had to complete each week to maximise their ability to engage with the text in the light of their caring responsibilities, which sometimes changed dramatically week to week. [study author, MS, ACT intervention, (Potter et al., 2021)]

Challenges with acceptance and readiness

With neurodegenerative diseases, acceptance of the diagnosis and progressive symptoms can happen gradually and at different stages, and this influences how willing and how well participants can engage with interventions. Participants described how accepting the diagnosis and thinking about the future and symptom progression is difficult and anxiety provoking (Bogosian et al., 2016; de Wit et al., 2019; Douglas et al., 2021; Fitzpatrick et al., 2010; Gottberg et al., 2016; Johannessen et al., 2015; Johnston et al., 2016; Larochette et al., 2020; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Vandenberg et al., 2019). Intervention activities that triggered thoughts about the future and progression could also be challenging. For example, participants reported being anxious about meeting people with the same condition or finding out about other people's experiences, as this may show them what might happen to them in the future (Berk et al., 2019; Bogosian et al., 2016; de Wit et al., 2019; Eccles et al., 2020; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Simpson et al., 2018).

Everybody seemed to be worse than me and I thought 'I don't think this is going to work for me' I've said before, 'if I don't see it I haven't got it'. There was one lady who said 'come and join us at the Parkinson's society' and I thought 'I'm not ready for that'. [person with Parkinson's disease, mindfulness intervention, (Fitzpatrick et al., 2010)]

Similarly, some caregivers found interventions that discussed end-of-life issues and aggressive or disruptive behaviours in the case of dementia difficult and tried to avoid that section of the intervention (de Wit et al., 2019; Johannessen et al., 2015). Activities like mindfulness can trigger difficult thoughts about one's own disability or impairment (Johnston et al., 2016; Martin et al., 2015; Simpson et al., 2018; Simpson et al., 2019). Some interventions tried to avoid provoking distress by framing the intervention activities in more positive and less confronting ways (Johnston et al., 2016; Martin et al., 2015). For example, a 'memory box' activity was presented as a place to put happy memories

and a goal-setting activity was presented as a way to focus on doing positive things in the future, and participants in this particular intervention found these two activities useful (Martin et al., 2015). Even though some intervention components such as group support or mindfulness were described as challenging, participants also reported that they were useful in increasing their acceptance of the disease and encouraged them to be more open about their situation (Bogosian et al., 2016; Fitzpatrick et al., 2010; Johannessen et al., 2015; Lavoie et al., 2005; Pegler, 2017; Vandenberg et al., 2019).

The 'memory box' activity, which was demonstrated by the course champion, was something some participants already did. Others felt worried this was linked to thinking about death. The tutors reemphasized that the focus of the activity was on having a place where photographs or items relating to happy memories are kept and used as a resource to enjoy. Additionally, the activities around increasing happiness and sharing successes were seen positively as they both drew attention to previous achievements and current strengths. [study author, dementia, psychoeducation intervention, (Martin et al., 2015)]

Being aware of the impact of the disease can be a necessary step to engaging with psychological interventions. Participants who were struggling to cope with the disease, felt a stronger need for the intervention (Giovannetti et al., 2020; Gottberg et al., 2016; Kazmer et al., 2018; Simpson et al., 2019; Tahsin et al., 2021). Those who did not currently experience too many problems as a result of the disease did not feel the need for psychological support (de Wit et al., 2019; Dennison et al., 2013; Gottberg et al., 2016; Hind et al., 2010; Pegler, 2017; Simpson et al., 2018). This was particularly true for people at the early stages of the disease, but there were some exceptions where the intervention at an early stage helped prepare participants for future challenges (Adams, 2018; de Wit et al., 2019; Dennison et al., 2013; Simpson et al., 2018). Some participants at a more advanced stage also felt that they would have benefitted from accessing the intervention earlier on (de Wit et al., 2019; Han et al., 2021; Johannessen et al., 2015; Nehrig, Gillooly, et al., 2019). Some suggested introducing the intervention early and then re-examining content as they encountered specific difficulties (de Wit et al., 2019; Dennison et al., 2013; Eccles et al., 2020; Han et al., 2021; Johnston et al., 2016).

Those 6 weeks, they really helped to sort things out again. But you gradually notice that you start to forget things. Things change so much with ALS. When I look at how I experienced it in the beginning and in the final phase, it is so different. So I would like to give it as advice to offer the program several times. It simply helps you to make conscious choices. [caregiver for person with MND, ACT intervention, (de Wit et al., 2019)]

It was also important to be open-minded, willing to try something new, and be willing to address difficult thoughts and feelings (Bogosian et al., 2021; Dennison et al., 2013; Giovannetti et al., 2020; Gottberg et al., 2016; Larochette et al., 2020; Nehrig, Shifrin, et al., 2019; Pegler, 2017; Sessanna et al., 2021). Although important, this can be difficult to do and some feared that addressing difficult situations and emotions might make them unhappy (Berk et al., 2019; Bogosian et al., 2016; Larochette et al., 2020). There was some scepticism about the benefit of a psychological intervention when there was little to do to change the course of the disease and participants felt that this needed to be explained more clearly (Adams, 2018; Berk et al., 2019; Douglas et al., 2021; Eccles et al., 2020; Giovannetti et al., 2020; Gottberg et al., 2016; Martin et al., 2015; Simpson et al., 2019).

One factor that appeared to influence whether a participant benefited from and was satisfied with their therapy experience was the degree to which they related to and engaged with the approach. Participants identified this as 'buying into' therapy and described being open-minded, willing to open up to the therapist and give the approach a fair chance as important. [study author, MS, CBT intervention, (Dennison et al., 2013)]

Introductory sessions can be useful for preparing participants for the intervention and setting expectations about the time, commitment, likely benefits, and doing intervention activities in the context of disability/impairment (Bogosian et al., 2021; de Wit et al., 2019; Dennison et al., 2013; Douglas et al., 2021; Gottberg et al., 2016; Johannessen et al., 2015; Martin et al., 2015; Simpson et al., 2018; Simpson et al., 2019).

Benefits: changes in insight, perspective, self-efficacy, emotions and relationships

People with neurodegenerative diseases and caregivers reported a number of benefits from psychological interventions. The interventions helped participants become more open and accepting of the impact of the disease (Adams, 2018; Berk et al., 2019; Bogosian et al., 2016; Bogosian et al., 2021; Craig et al., 2018; de Wit et al., 2019; Dennison et al., 2013; Douglas et al., 2021; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Gottberg et al., 2016; Hoppes et al., 2012; Johannessen et al., 2015; Kazmer et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Nehrig, Shifrin, et al., 2019; Pegler, 2017; Simpson et al., 2018; Simpson et al., 2019; Swannell, 2017; Vandenberg et al., 2019). They were more self-aware, particularly of their thoughts and how this impacted their feelings and responses to situations (Berk et al., 2019; Bogosian et al., 2016; Dennison et al., 2013; Douglas et al., 2021; Eccles et al., 2020; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Gottberg et al., 2016; Han et al., 2021; Swannell, 2017; Vandenberg et al., 2019). This awareness or insight was key to changing their perspective on the disease and their situation. They thought about their disease or situation differently, and considered other perspectives (Adams, 2018; Bogosian et al., 2016; Bogosian et al., 2021; de Wit et al., 2019; Dennison et al., 2013; Giovannetti et al., 2020; Gottberg et al., 2016; Hoppes et al., 2012; Johnston et al., 2016; Larochette et al., 2020; Marconi et al., 2016; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Vandenberg et al., 2019). This perspective-taking was an important part of coping especially when there was no cure or treatment. Participants developed a more self-compassionate and positive approach to coping with neurodegenerative diseases. They placed more value on themselves and carved time out for self-care, (Berk et al., 2019; Bogosian et al., 2016; Craig et al., 2018; de Wit et al., 2019; Dennison et al., 2013; Douglas et al., 2021; Giovannetti et al., 2020; Glueckauf et al., 2012; Han et al., 2021; Kazmer et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Pegler, 2017) were less critical or kinder to themselves, (Adams, 2018; Craig et al., 2018; Dennison et al., 2013; Douglas et al., 2021; Han et al., 2021; Simpson et al., 2018; Simpson et al., 2019; Swannell, 2017) and focused on the things they could still do, appreciated things more, and overall developed a more positive outlook (Bogosian et al., 2016; Dennison et al., 2013; Douglas et al., 2021; Hoppes et al., 2012; Martin et al., 2015; Pegler, 2017; Sessanna et al., 2021; Simpson et al., 2018).

Yes, I'd say I'm more at ease with my situation. I can accept things more the way they are and think it's OK. [person with MS, CBT intervention, (Gottberg et al., 2016)]

I think I remind myself now ... that I'm actually doing a good job. Looking after my mum and everything else I'm dealing with ... and sometimes I forget and I take a step back and I think "damn, you've been through a lot." So cut yourself some slack ... [caregiver for person with dementia, compassion-focused therapy, (Craig et al., 2018)]

Participants felt more in control of their lives, more confident about caring tasks, and expressed that they were 'coping better'. They valued learning skills and strategies and having the tools to manage difficult thoughts and feelings when they came up (Adams, 2018; Berk et al., 2019; Bogosian et al., 2016; de Wit et al., 2019; Dennison et al., 2013; Douglas et al., 2021; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Glueckauf et al., 2012; Gottberg et al., 2016; Han et al., 2021; Hoppes et al., 2012; Kazmer et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Marconi et al., 2016; Martin et al., 2015; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Potter et al., 2021; Sessanna et al., 2021; Simpson et al., 2019; Swannell, 2017; Tahsin et al., 2021; Vandenberg et al., 2019). This included being able to give negative thoughts less attention (Berk et al., 2019; Bogosian et al., 2016; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Han et al., 2021; Marconi et al., 2016; Vandenberg et al., 2019) and being able to choose how they respond to situations (Bogosian et al., 2016; Dennison et al., 2013; Douglas et al., 2021; Fitzpatrick et al., 2010; Han et al., 2021; Hoppes et al., 2012; Marconi et al., 2016; Simpson et al., 2018; Swannell, 2017; Vandenberg et al., 2019). Some also reported being better able to deal with certain physical symptoms like fatigue, pain, tremors (Bogosian et al., 2021; Dennison et al., 2013; Fitzpatrick et al., 2010; Gottberg et al., 2016; Simpson et al., 2018) and

improved sleep (Bogosian et al., 2021; Giovannetti et al., 2020; Gottberg et al., 2016; Marconi et al., 2016; Sessanna et al., 2021; Simpson et al., 2018; Tahsin et al., 2021).

Through learning to be mindful, participants gained freedom to choose how they wished to respond to situations. This choice was empowering as people gained control over themselves and their responses. [study author, MS, mindfulness intervention, (Bogosian et al., 2016)]

People with neurodegenerative diseases felt confident about dealing with disease-related challenges (Adams, 2018; Dennison et al., 2013; Giovannetti et al., 2020; Gottberg et al., 2016; Johnston et al., 2016; Sessanna et al., 2021; Vandenberg et al., 2019) and caregivers felt confident about problem-solving and preparing for future challenges (de Wit et al., 2019; Glueckauf et al., 2012; Han et al., 2021; Johannessen et al., 2015; Johnston et al., 2016; Kazmer et al., 2018; Larochette et al., 2020; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Pegler, 2017). Caregiver participants recognised when they needed help and felt able to find or ask for help in these situations (de Wit et al., 2019; Glueckauf et al., 2012; Han et al., 2021; Johannessen et al., 2015; Kazmer et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Swannell, 2017). Participants were able to identify what was important or meaningful to them and pursue these goals or activities (de Wit et al., 2019; Dennison et al., 2013; Giovannetti et al., 2020; Han et al., 2021; Martin et al., 2015).

The findings show that the intervention contributed to making the caregivers feeling safer, giving them a better understanding of the disorder. Also, the intervention helped them to be more open about their situation and more prepared for the future. [study author, dementia, psychoeducation intervention, (Johannessen et al., 2015)]

Other benefits included feeling acknowledged and understood (Craig et al., 2018; de Wit et al., 2019; Dennison et al., 2013; Douglas et al., 2021; Giovannetti et al., 2020; Kazmer et al., 2018; Lavoie et al., 2005; Marconi et al., 2016; Martin et al., 2015; Potter et al., 2021), feeling calm and less stressed or anxious (Berk et al., 2019; Bogosian et al., 2021; Craig et al., 2018; Douglas et al., 2021; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Hoppes et al., 2012; Marconi et al., 2016; Nehrig, Shifrin, et al., 2019; Potter et al., 2021; Simpson et al., 2018; Tahsin et al., 2021), positive effects on self-esteem (Giovannetti et al., 2020; Martin et al., 2015), reduced caregiver burden and feelings of guilt (Han et al., 2021; Hoppes et al., 2012; Johannessen et al., 2015; Lavoie et al., 2005).

Some reported an improvement in their relationships, where there was more understanding between the person with the neurodegenerative condition and family, (de Wit et al., 2019; Douglas et al., 2021; Hoppes et al., 2012; Kazmer et al., 2018; Larochette et al., 2020; Nehrig, Shifrin, et al., 2019; Vandenberg et al., 2019) less conflict, (Berk et al., 2019; Giovannetti et al., 2020; Han et al., 2021; Hoppes et al., 2012; Kazmer et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Nehrig, Gillooly, et al., 2019; Nehrig, Shifrin, et al., 2019; Pegler, 2017; Simpson et al., 2018) less isolation, (Berk et al., 2019; Douglas et al., 2021; Swannell, 2017) more connection and communication, (Adams, 2018; Berk et al., 2019; Craig et al., 2018; Larochette et al., 2020; Lavoie et al., 2005; Marconi et al., 2016; Swannell, 2017) more openness, (Bogosian et al., 2021; de Wit et al., 2019; Giovannetti et al., 2020; Sessanna et al., 2021; Vandenberg et al., 2019) and overall better interactions with others (Berk et al., 2019; Giovannetti et al., 2020; Hoppes et al., 2012; Simpson et al., 2018; Vandenberg et al., 2019). Participants felt more confident with social interactions, and did not avoid social situations (Dennison et al., 2013; Fitzpatrick et al., 2010; Giovannetti et al., 2020; Johannessen et al., 2015; Vandenberg et al., 2019).

Some participants reported that the training had influenced their relationship as a couple. Caregivers were better able to prevent or deal with quarrels. They felt more connected. [study author, dementia, mindfulness intervention, (Berk et al., 2019)]

Although majority of the studies reported intervention benefits, few participants in some studies said that they did not notice any changes post-intervention (Berk et al., 2019; Craig et al., 2018; Dennison et al., 2013; Douglas et al., 2021; Potter et al., 2021).

A minority of participants reported little or no change from therapy. This tended to be more common for the SL (supportive listening – control group) participants and those who disagreed with the logic of their intervention. Other participants felt that they were already coping very well with MS, and so found they had little to gain from therapy. [study author, MS, CBT intervention, (Dennison et al., 2013)]

Discussion

We synthesised the experiences of people with neurodegenerative diseases and caregivers and identified barriers and facilitators that are relevant to engagement and acceptability of psychological interventions. Many participants valued the post-intervention changes in insight, perspective, self-efficacy, emotions and relationships. However, important things to consider include adequate levels of intervention tailoring and flexibility, intervention accessibility and burden, and challenges with acceptance and readiness among participants. The four themes presented in this review need to be considered in conjunction when developing or evaluating interventions, as they can interact with each other. For example, adequate tailoring might help reduce intervention burden; insight and perspective may be valued outcomes but may depend on acceptance or readiness from participants; or accessibility can be improved with dedicated tailoring strategies. Table 3 summarises key considerations when developing engaging and acceptable interventions for people with neurodegenerative diseases and caregivers based on the findings from our review.

With neurodegenerative diseases, it is important to tailor intervention content to the specific disease and adapt activities or advice so that people with various physical and cognitive symptoms

Table 3. Key considerations when developing psychological interventions for people with neurodegenerative diseases and caregivers.

Key things to consider	
Intervention personalisation	It is important not to treat people with a particular neurodegenerative disease or their caregivers as a homogenous group as there can be differences in symptoms experienced, coping styles, levels of readiness to engage with interventions, and preferences for therapy. Interventions could be personalised by asking people about their needs and preferences and then tailoring interventions, or allowing individuals to self-tailor the intervention to meet their needs (e.g., choosing or prioritising from a choice of content and activities).
Intervention accessibility and burden	Intervention content and activities need to be accessible to people with different physical and cognitive symptoms. This includes thinking about and improving the accessibility of intervention materials, session durations, homework tasks, different modes of intervention delivery. To make interventions less burdensome, intervention durations can be minimised, some activities can be optional, and information and suggestions need to be easy to integrate into users' daily routine.
Intervention flexibility and responsiveness	As symptoms change, users' needs may also change and interventions need to take this into account and respond to these new needs. Offering support at different points in the disease trajectory allows for people with neurodegenerative diseases and caregivers to take up the offer when they feel ready or as symptoms and needs change.
Introduction and setting expectations	Familiarity with and understanding the benefits of psychological therapy can improve engagement (Liu & Gellatly, 2021; Theed et al., 2018), and explaining this through introductory sessions or intervention promotion materials or testimonies from peers may help engage users and alleviate anxieties in individuals who are unsure of what therapy would entail or do not feel ready to take part. Explaining the time and commitment involved with taking part in the intervention can also help users' understand what to expect from the intervention.
Focus on engagement and acceptability when developing and evaluating interventions	It is important to examine how users engage with the intervention and be open to exploring issues with acceptability. Adopting user-centred or co-production approaches when designing interventions for people with neurodegenerative diseases and caregivers may be useful for anticipating potential barriers to engagement and evaluating the acceptability of intervention adaptations.

can participate and feel that the intervention is designed for the problems and context they are facing. Disease-specific therapy manuals have been developed and used to improve psychological outcomes for patients and caregivers in some neurodegenerative diseases like Parkinson's disease, dementia, and MS (Chan et al., 2017; Dobkin et al., 2007; Moss-Morris et al., 2013). However, psychological support interventions need to move beyond a one-size-fits-all approach for specific disorders and personalise interventions based on individual and contextual factors (Purgato et al., 2021). Our findings show that additional tailoring and flexibility is required with interventions for neurodegenerative diseases because of the variability in symptoms, disease stages, coping preferences, and preferences for therapy. Individual differences in terms of levels of acceptance and readiness are also important considerations, particularly with neurodegenerative conditions, where thinking about disease progression can be distressing (Moss-Morris et al., 2013). People with neurodegenerative diseases can experience rapid changes in their medical and psychological condition, and therefore their needs within different phases in psychological interventions may also change. Although this level of personalisation of interventions is important, it may also be challenging to execute in very structured, manualised therapies or in interventions that are conducted in a group setting, compared to one-to-one interventions facilitated by trained professionals. Our review also found very few interventions that offered individuals a choice regarding the type of therapy and therapeutic activities. Having options for different kinds of psychological support could be a way forward to further personalise interventions by allowing people to choose content and activities that match their needs and preferences.

Recent reviews of the effectiveness of psychological interventions for wellbeing in neurodegenerative diseases noted that so far there is more evidence for certain therapeutic approaches (e.g., CBT and mindfulness) and less research on other therapeutic approaches (Zarotti, Eccles, et al., 2020; Zarotti, Mayberry, et al., 2020). Our current synthesis of intervention experiences mirrors the types of interventions covered in these reviews with mindfulness-based interventions being most common. Noteworthy in our review is the use of therapeutic approaches that originate from clinical psychology, and few studies that use health psychology theory and frameworks. Health psychology approaches often have a focus on beliefs about the disease or symptoms, and cognitive and behavioural strategies in relation to illness-related threats (e.g., Leventhal's common-sense model of self-regulation or Moss-Morris' model of adjustment to chronic illness) (Leventhal et al., 1998; Moss-Morris, 2013). Our review showed that some beliefs about the illness, particularly how people thought about future disease progression and the level of acceptance of the impact of the illness on their life can also play a role in how people engage with interventions. Integrating theoretical frameworks from health psychology and psychological therapy models can potentially improve engagement and make intervention programmes more effective (Karekla et al., 2019).

There also needs to be greater flexibility with how psychological interventions are delivered for people with neurodegenerative diseases and caregivers. Therapists working with long-term conditions have expressed a need for a model of therapy that has greater flexibility in terms of session frequency, attendance policies, mode of delivery, and session location because of issues with mobility, unpredictable symptoms, time involved and fatigue (Carroll et al., 2021). Additionally, physical and cognitive symptoms can make engaging with therapy difficult or burdensome for people with neurodegenerative diseases (Dennison & Moss-Morris, 2010; Dobkin et al., 2013; Van Groenestijn et al., 2015). With psychological interventions, the structure and timing of sessions, and aspects such as homework can act as barriers to starting or continuing therapy (Barnes et al., 2013; Rice et al., 2020). Being flexible with the structure of psychological services or providing necessary resources/support can help reduce this treatment burden (May et al., 2014; Rice et al., 2020). Carefully considering a biopsychosocial framework when developing interventions (biological aspects – e.g., changes in symptoms, psychological aspects – e.g., level of acceptance, social aspects – e.g., support from services or family) could also guide interventions to be more flexible in terms of their delivery.

Based on our review findings, we have made some recommendations for future research. Going forward researchers need to focus on issues with engagement and acceptability when developing interventions for people with neurodegenerative diseases and caregivers. User needs should be evaluated using qualitative methods by adopting a more user-centred or co-production approach. There is a gap in our understanding of how engagement differs with different types of psychological interventions and with different methods of intervention delivery, and how different levels of engagement can impact outcomes. This needs to be explored in future research. We also recommend more detailed and consistent reporting of intervention development, content, and delivery, including the steps taken to adapt or tailor the intervention to specific populations as this can impact the acceptability and engagement with the intervention. Our review highlighted the range of benefits people with neurodegenerative diseases and caregivers experience from psychological interventions, which go beyond changes usually anticipated in trials such as improvements in mood or well-being. It would be useful to measure these broader changes (e.g., changes in self-awareness, thinking and attitudes, self-efficacy) quantitatively as outcomes of intervention trials (Berk et al., 2019; Eccles et al., 2020; Meek et al., 2021; Nehrig, Gillooly, et al., 2019; Tang & Chan, 2016) as well as undertake research to determine what outcomes are valued or appropriate to use as indicators of therapeutic success, especially in progressive diseases where symptoms will get worse with time.

Strengths and limitations

Analysing data from qualitative studies provided a unique insight into issues of acceptability and engagement, and we were able to identify common factors that impact acceptability and engagement across different neurodegenerative diseases. We also need to be conscious that these studies may represent experiences of those who have agreed to take part in a psychological intervention and agreed to give feedback. There may be other barriers or views among those who did not take part, or who dropped out or did not benefit from the intervention. It is not always easy to capture these perspectives through research studies, however, we need to be cognisant that the review findings may present a more optimistic view of participants' experiences.

The majority of the interventions were mindfulness-based, conducted face-to-face and in a group setting. Some of the facilitators and barriers identified by this review may have been influenced by this. For example, difficulties with accessibility and burden may reflect the group and face-to-face format as well as the relatively longer duration of sessions. Additional research with other intervention types and formats may yield different insights into engagement issues. The majority of the studies included people/caregivers of people with dementia or MS and this may have influenced review findings. However, after assessing confidence in each of the review themes, we are confident that our findings did not come solely from particular diseases but were derived from experiences across the different neurodegenerative diseases.

Conclusion

We have identified specific barriers and facilitators to using psychological interventions with people with neurodegenerative diseases and their family/informal caregivers. It was important to tailor information and advice beyond the specific neurodegenerative disease and be flexible to participants' needs and preferences. This was particularly important so that interventions were accessible to people with different physical and cognitive symptoms, and so that interventions were not experienced as burdensome. Different levels of acceptance and readiness can make intervention engagement and acceptability challenging and interventionists need to be sensitive to this and adapt the intervention or their approach accordingly. Once these factors are considered, individuals can experience wide-ranging benefits from psychological interventions including changes in insight, perspective, self-efficacy, emotions and relationships. It is useful to consider and measure the

range of potential benefits from psychological interventions, especially with neurodegenerative diseases where physical deterioration and limited prognoses can make interpreting the outcomes of psychological interventions more challenging.

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Notes on contributors

Cathryn Pinto designed the review protocol, conducted the searches, screened the search results for inclusion, extracted the data, conducted the quality assessment and GRADE CERQual assessment, carried out a thematic synthesis of the data, drafted the paper and has approved the final manuscript.

Dr **Adam W. A. Geraghty** contributed to the design of the review, development of search strategy, and review methods, advised on the data extraction and quality assessment, contributed to the thematic synthesis and presentation of the results, and provided feedback and approved the final manuscript of the paper.

Charlotte McLoughlin undertook the title and abstract screening and full-text screening of the search results, and provided feedback and approved the final manuscript of the paper.

Dr **Francesco Pagnini** provided feedback on the results of the thematic synthesis, contributed to and approved the final manuscript of the paper.

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