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Cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in progressive neurodegenerative conditions: a scoping review

Linda Clare[1,2,3], Julia C. Teale[1,2], Gill Toms[4], Aleksandra Kudlicka[1,2], Isobel Evans[1], Sharon Abrahams[5], Laura H. Goldstein[6], John V. Hindle[4], Aileen K. Ho[7], Marjan Jahanshahi[8], Dawn Langdon[9], Robin Morris[6], Julie S. Snowden[10], Rhys Davies[11], Ivana Markova[12], Monica Busse[13] and Jo Thompson-Coon[2]

1. Centre for Research in Ageing and Cognitive Health, University of Exeter
2. PenCLAHRC, University of Exeter Medical School
3. Centre for Research Excellence in Cognitive Health, Australian National University
4. School of Psychology, Bangor University
5. Psychology-PPLS, Euan MacDonald Centre for Motor Neurone Disease Research, The University of Edinburgh
6. King's College London, Institute of Psychiatry, Psychology and Neuroscience
7. School of Psychology and Clinical Language Sciences, University of Reading
8. Institute of Neurology, University College London
9. Royal Holloway University of London
10. University of Manchester
11. Walton Centre NHS Foundation Trust
12. University of Hull
13. Cardiff University

Corresponding author

Professor Linda Clare, Centre for Research in Ageing and Cognitive Health (REACH), School of Psychology, University of Exeter, Perry Road, Exeter EX4 4QG, UK

l.clare@exeter.ac.uk

http://www.psychology.exeter.ac.uk/REACH

Cognitive rehabilitation for people with progressive neurodegenerative conditions and cognitive disability: a scoping review

Abstract

BACKGROUND: Despite their potentially significant impact, cognitive disability may be overlooked in a number of progressive neurodegenerative conditions, as other difficulties dominate the clinical picture.

OBJECTIVE: We examined the extent, nature and range of the research evidence relating to cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in Parkinsonian disorders, multiple sclerosis (MS), frontotemporal dementias (FTD), motor neuron disease and Huntington's disease.

METHODS: Scoping review based on searches of MEDLINE and CINAHL up to 15 March 2016.

RESULTS: We included 140 eligible papers. Over half of the studies, and almost all the randomised controlled trials, related to MS, while a number of single case studies described interventions for people with FTD. CR interventions addressed functional ability, communication and interaction, behaviour or memory. The majority of psychotherapy interventions involved cognitive behavioural therapy for depression or anxiety. Self-management interventions were mainly available for people with MS. There were few reports of interventions specific to caregivers. Numerous methodological challenges were identified.

CONCLUSIONS: The limited range of studies for all conditions except MS suggests a need firstly to synthesise systematically the available evidence across conditions and secondly to develop well-designed studies to provide evidence about the effectiveness of CR and other psychological interventions.

Keywords: Parkinson's disease, multiple sclerosis, frontotemporal dementia, motor neuron disease, Huntington's disease, self-management, psychotherapy, caregiver

1. Introduction

Progressive neurodegenerative conditions (PNCs), many age-related, affect over a million people in the UK alone and often result in cognitive disability. It is unrealistic to assume that there will be an early cure or means of prevention for all, or even most, progressive neurodegenerative conditions. Therefore, there is an urgent need for strategies that go beyond supportive care and enable people to function at the best level possible and to live well with cognitive disability resulting from neurodegenerative disease. Here we focus on five progressive neurodegenerative conditions in which cognitive disability, in some cases amounting to dementia, forms a significant part of the clinical picture. These are the Parkinsonian disorders (PDs) including Parkinson's disease (PD), progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal degeneration (CBD) and dementia with Lewy Bodies (DLB), multiple sclerosis (MS), the frontotemporal dementias (FTDs) including behavioural variant FTD, semantic dementia (SD) and primary progressive aphasia (PPA), motor neuron disease (MND), and Huntington's disease (HD). We selected these five conditions, with a focus on the adult and older adult population, because they are amongst the commoner of the neurodegenerative diseases which apart from motor symptoms and behavioural changes are also characterised by significant albeit variable cognitive impairment. Alzheimer's disease is not covered here because of the already extensively-reviewed research (Bahar-Fuchs, Clare, & Woods, 2013; Clare, 2008; Morris & Becker, 2004).

Cognitive impairment is integral to FTDs and HD, and affects a significant proportion of people diagnosed with MND, PDs, and MS. Cognitive impairments progress in extent and severity over time, although the rate of progression is variable across conditions and across individuals affected, and does not always correspond with the staging of physical symptoms. In FTDs, HD, and most PDs, cognitive impairments progress to full dementia (Hindle,

Petrelli, Clare, & Kalbe, 2013), but this is rare in MS, and in MND occurs only where there is co-morbid FTD. Although the five conditions are very different in many respects, and have different pathogenic origins and affect different neural networks, there are common elements in terms of the underlying cognitive processes that are impaired. Table 1 summarises the cognitive domains affected and the behavioural and emotional features arising in each of the five conditions and demonstrates the extensive overlap in presentations.

(((Table 1)))

Impaired cognitive processes have wide-ranging effects. They may result in behavioural problems; for example, impaired executive function can involve poor judgement and decision-making, and can be associated with a loss of initiation and generation leading to apathy. Impaired cognition also contributes to the pathophysiology of motor symptoms; for example, problems with attention and conflict resolution contribute to mobility problems in PDs such as freezing of gait (Vandenbossche et al., 2011). Equally, motor symptoms may add to the cognitive challenges of daily life.

Cognitive changes, and the progression of cognitive impairment in some of these disorders, significantly affect important aspects of everyday life and well-being, including everyday functioning and behaviour (Birnboim & Miller, 2004; Goretti, Portaccio, Zipoli, Razzolini, & Amato, 2010; Goverover, Chiaravalloti, & DeLuca, 2016; Goverover, Haas, & DeLuca, 2016; Pirogovsky et al., 2014), employment (Benedict et al., 2016), communication and social interaction (Anderson, Simpson, Channon, Samuel, & Brown, 2013; Cavallo et al., 2011; Eddy, Mahalingappa, & Rickards, 2014; Meier, Charleston, & Tippett, 2010; Merrilees, Klapper, Murphy, Lomen-Hoerth, & Miller, 2010; Palmieri et al., 2010),

involvement in decision-making (Abrahams, 2011; Martin et al., 2014; Meier et al., 2010; Merrilees et al., 2010), disease management (Bruce, Hancock, Arnett, & Lynch, 2010), and emotional well-being and quality of life (Ho, Gilbert, Mason, Goodman, & Barker, 2009; Ready, Mathews, Leserman, & Paulsen, 2008; Schrag, Jahanshahi, & Quinn, 2000; Shatil, Metzer, Horvitz, & Miller, 2010). Cognitive changes have a major impact on the family members of those living with these conditions, and cognitive impairment is associated with caregiver burden and reduced caregiver quality of life (Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014; Morley et al., 2012; Ready et al., 2008), as are other psychiatric symptoms (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Some people may lack awareness of changes or difficulties, especially in FTD and HD, which can add considerably to caregiver burden. Depression is common among people with HD, MS and PDs (Burn, 2002; Siegert & Abernethy, 2005; Slaughter, Martens, & Slaughter, 2001), and anxiety is also frequent in MS (Korostil & Feinstein, 2007), while people with FTDs and MND may also experience low mood (Blass & Rabins, 2009; Goldstein, Atkins, & Leigh, 2002).

Because of the predominance of other difficulties, such as progressive motor system dysfunction (PDs, HD, MS, and MND) or behaviour and personality change (FTD and HD), the impact of cognitive change in these conditions is often underestimated and under-recognised. Furthermore, with the exception of FTD, people living with these conditions who have cognitive impairments are often excluded from intervention studies (Goodwin & Lan, 2014). Consequently, there is limited guidance available that can inform clinicians and those living with or affected by these conditions about effective non-pharmacological ways of managing the impact of cognitive impairment and supporting optimal functioning. Appropriate

pharmacological treatment where indicated is of course essential, but here we focus on non-pharmacological approaches.

Importantly, strategies for managing the effects of cognitive impairment and optimising functioning are not condition-specific. The application of common strategies can be tailored to the specific needs of the population and the individual, for example by making adaptations to account for motor or sensory limitations. This means that evidence from a range of conditions could potentially be assembled to provide professionals with practical guidance that enables them to work flexibly across conditions, drawing on the commonalities that can be observed.

Rehabilitation is key to managing cognitive and behavioural disability and optimising functioning. Rehabilitation for people with cognitive disability, termed 'cognitive rehabilitation' (CR) and sometimes also referred to as 'reablement', focuses on enabling each individual to function at his/her optimal level given the nature and extent of cognitive impairment, and to remain engaged with an appropriate social context (Beaumont & Morris, 2005). CR uses a goal-oriented approach to facilitate improved management of the consequences of functional disability, and has already been successfully applied to assist people with dementia due to Alzheimer's or vascular disease (Bahar-Fuchs et al., 2013; Clare et al., 2013; Clare et al., 2010). Key elements are an individualised formulation, collaborative identification of specific realistic and meaningful goals, application of evidence-based behavioural strategies, and adjustment of goals and strategies in response to changes in the person's condition. The rehabilitation therapist assesses the person's current ability and the demands of the activity the person wishes or needs to do, identifies where mismatches arise, and collaboratively develops a therapy plan to support goal attainment. While rehabilitation goals may be very different depending on condition, stage and degree of severity, the overall

aims of supporting independence and self-determination, and the repertoire of behavioural methods and techniques employed to support goal attainment, are likely to be similar.

Cognitive rehabilitation is complemented by three other key related psychosocial intervention approaches:

- Access to psychological therapies to address mental health needs such as anxiety or depression, and support the process of adjustment to living with a neurodegenerative condition. This may be a vital precursor to enabling participation in cognitive rehabilitation interventions.
- Providing information about the condition and encouraging an appropriate degree of self-management. This encompasses support for decision-making and planning for future care needs, including end-of-life care where relevant, and may include facilitating opportunities for social contact and engagement in enjoyable and meaningful activities. Greater understanding of a condition can facilitate engagement with rehabilitation.
- Support for caregivers. Effective support for caregivers includes provision of information, advice, emotional support and skills training, enabling them to support the process of cognitive rehabilitation and to provide optimal care that promotes the functioning, independence and self-determination of the person with cognitive impairment.

While pharmacological interventions play a part in the management of cognitive and behavioural difficulties, and can facilitate participation in non-pharmacological interventions, the indications for and efficacy of such treatments represent a complex and specialised topic that is beyond the scope of the present review. Here we focus on non-pharmacological approaches.

Drawing together the evidence for the efficacy of rehabilitation interventions, together with associated domains of self-management, psychotherapeutic and caregiver support interventions, across the five PNCs, could provide a basis for developing guidance for health and social care professionals, and information for patients and carers living with PNCs, and could identify gaps in knowledge to be addressed by further research. While reviews have examined the efficacy of specific interventions for one or more conditions (Croot, Nickels, Laurence, & Manning, 2009; Fernie, Kollmann, & Brown, 2015; Hindle et al., 2013; Langenbahn, Ashman, Cantor, & Trott, 2013; Rae-Grant et al., 2011) no review has yet integrated the evidence for cognitive rehabilitation and associated intervention approaches across all five conditions. Here we outline a scoping review (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014) undertaken to determine the feasibility of this approach and its potential for improving the quality of support available to people with these conditions and their caregivers. We defined our review question as: 'What is the extent, nature and range of the research evidence relating to the efficacy, experience and implementation of cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in PDs, MS, FTD, HD and MND?'

2. Materials and methods

In line with recommended scoping review methods, we aimed to map the application of key intervention concepts, and types of evidence available, in relation to people living with the conditions of interest and their caregivers by systematically searching, selecting and synthesising existing knowledge (Arksey & O'Malley, 2005) and to consider the implications for practice, within the constraints imposed by budgets and time availability (Levac et al., 2010). We adopted a broad focus and considered a wide range of study designs in order to

provide a descriptive overview of the available evidence (Pham et al., 2014). We consulted with people living with PNCs when formulating plans for the project.

We conducted searches in the MEDLINE and CINAHL databases on 15 and 23 January 2015, and updated searches on 15 March 2016, combining search terms designed to capture the relevant types of intervention and the conditions of interest. We selected these databases for pragmatic reasons, given time and budget constraints, as two of the largest and most widely-used sources likely to provide the most effective search results. Our target populations were people with one of the five PNCs or carers of people with one of the five PNCs. Target interventions were cognitive rehabilitation, psychological therapy or self-management, education or support interventions for people with one of the five PNCs, or education, skills training or support interventions for caregivers of people with one of the five PNCs. We considered any or no comparators, and any outcomes. Search terms covering populations and interventions are shown in table 2.

(((Table 2)))

Studies were included if a) participants had one of the five PNCs or were carers of people with one of these conditions; b) participants with PNCs who had cognitive impairment were included or not explicitly excluded; and c) the paper reported quantitative or qualitative data relating to a cognitive rehabilitation, psychological therapy or self-management, education or support intervention for people with one of the five PNCs, or an education, skills training or support intervention for caregivers of people with one of the five PNCs. For PDs and MS, searches were limited to the period from 2010 to the present due to the volume of records available for those conditions. Key studies known to the research team were also included.

Title, abstract and full-text screening was carried out by GT, JCT, AK and IE. The screening process was managed in EndNote ® Version 7. After merging search results from MEDLINE and CINAHL, duplicates were identified in Endnote first by using the default settings in 'Find duplicates' and then by adjusting the search criteria and inspecting reference lists ordered alphabetically by title and by author. At each stage of screening, each item was considered by at least two people working independently and any disagreements were discussed in order to reach a consensus. Where a lack of clarity remained, the item was referred to LC for a final decision. Eligible studies were grouped according to type as follows:

1. Cognitive rehabilitation interventions addressing cognitive or behavioural disability.
2. Psychological interventions addressing mood or adjustment to living with a neurodegenerative disorder.
3. Education, self-management and support interventions, including symptom management.
4. Education, skills training and support interventions for carers of people living with neurodegenerative disorder, such as carer support groups.

3. Results

Figure 1 provides a flowchart of the process of study identification and selection. Our searches yielded 19,187 unique records, of which 2,508 were retained for abstract screening and 731 were selected for full-text assessment. At this stage 154 papers were not readily obtainable and of the remaining 577 records, 140 reported relevant studies. Over half of the included studies focused on MS (74 studies, 53% of total). FTD (27 studies) accounted for 19%, PDs (19 studies) for 14%, HD (10 studies) for 7% and MND (10 studies) for 7% of the total. The included studies for each PNC are summarised by research design and by topic in table 3.

(((Figure 1)))

(((Table 3)))

To prepare a descriptive overview, the identified studies were grouped into the four intervention categories: cognitive rehabilitation (63 studies), psychological therapies for adjustment and mood (28 studies), education and self-management (42 studies), and support for carers (7 studies). A descriptive summary of the included studies, grouped by category and condition, is provided in table 4. Following the review of each category, methodological issues and challenges are considered.

(((Table 4)))

3.1. Cognitive rehabilitation

The cognitive rehabilitation interventions described were conducted either with individuals, in groups, or as part of multi-component treatment programmes. Interventions focused on functional ability, communication and interaction, behaviour or memory. Examples of studies using this approach were found across all five conditions. Of the 21 studies found involving people with FTD and SD, most were single case designs. Sample sizes ranged from 1 – 9. In contrast the 21 studies in MS (Gentry, 2008; Lincoln, Dent, & Harding, 2003; Lincoln et al., 2002) included 8 randomised controlled trials and sample sizes ranged from 1 – 240. There were 7 studies in HD (Mattern & Kane, 2007), of which 5 evaluated the effects of inpatient multidisciplinary team interventions and 2 were single case designs. There were 9 studies of PDs (Jain, Dawson, Quinn, & Playford, 2004), including one pilot RCT and one multi-centre RCT. For MND, there were 4 case studies (Kaiser et al., 2001) and one between groups

retrospective analysis including 344 people (Traynor, Alexander, Corr, Frost, & Hardiman, 2003).

Individualised, goal-oriented interventions to support everyday functioning, activities of daily living and self-care draw on compensatory methods such as the use of memory aids, restorative methods including techniques to help take in and recall information, such as spaced retrieval, and environmental adaptations (Buchanan, Christenson, Houlihan, & Ostrom, 2011). Studies examining the relative benefits of different techniques provide information about which strategies are most helpful for whom in which contexts (Goverover, Chiaravalloti, & DeLuca, 2008). Drawing on evidence about the efficacy of specific techniques and approaches, individual interventions are designed to address specific goals or needs, taking account of the individual's profile of strengths and limitations in cognitive and functional ability. Examples of studies using this approach were found across all five conditions.

Individualised, goal-oriented interventions to support communication and social interaction include the introduction of specific information processing strategies as well as the use of assistive communication aids and compensatory strategies and development of non-verbal communication skills (Croot et al., 2009; Kortte & Rogalski, 2013). Use of communication aids to enhance interaction was described for people with HD (Klasner & Yorkston, 2001). Extensive research in the FTDs applied a range of techniques to support relearning or maintenance of semantic knowledge (Bier et al., 2009; Dewar, Patterson, Wilson, & Graham, 2009; Dressel et al., 2010; Jokel & Anderson, 2012; Jokel, Rochon, & Leonard, 2006; Newhart et al., 2009; Robinson, Druks, Hodges, & Garrard, 2009; Savage, Ballard, Piguet, & Hodges, 2013; Savage, Piguet, & Hodges, 2015; Snowden, Kindell, Thompson, Richardson, & Neary, 2012; Snowden & Neary, 2002; Suárez-González et al., 2015). Some studies considered

maintenance of gains and transfer to everyday life (Bier et al., 2009; Robinson et al., 2009; Savage et al., 2013).

Individualised, goal-oriented interventions for behaviour are based on an individual formulation and on an understanding of the antecedents, consequences and functions of the given behaviour, and can help to reduce the impact of behavioural changes and hence support everyday functioning, relationships and social interactions. Techniques include introducing distraction and controlling triggers, as well as implementing environmental modifications, aids and adaptations (Croot et al., 2009). The use of this approach was reported for people with FTD and MND (Cleary, 2008; Fick, van der Borgh, Jansen, & Koopmans, 2014).

Cognitive rehabilitation interventions for memory and other cognitive difficulties were reported mainly in MS, often using a group format. These interventions, for people with mild to moderate impairments in memory, attention or executive function, encourage the use of compensatory and restorative strategies, environmental adaptations, and assistive technology. Included studies targeted self-efficacy and strategy use (Shevil & Finlayson, 2009, 2010; Stuifbergen et al., 2012) and subjective memory problems (Carr, das Nair, Schwartz, & Lincoln, 2014).

Cognitive rehabilitation forms a component of some multi-disciplinary rehabilitation programmes. Rehabilitation programmes conducted on an in-patient or out-patient basis may include a focus on addressing the consequences of cognitive impairments, although it is often not possible to determine the extent to which this contributes to the overall outcomes. Such programmes have been reported for example in HD, aiming to reduce disability and improve

participation and quality of life (Frich, Røthing, & Berge, 2014; Piira et al., 2013; Thompson et al., 2013; Zinzi et al., 2007).

3.2. Psychological interventions for adjustment and mood

The majority of studies were found in MS; of 17 included studies, 7 were RCTs. Fourteen studies evaluated the effects of cognitive behavioural therapy (Mohr et al., 2005) and 2 focused on acceptance and commitment therapy (Nordin & Rorsman, 2012). The majority of these were individual interventions, although there were also some group-based interventions addressing anxiety and depression, using approaches such as CBT, mindfulness, or acceptance and commitment therapy. There were 5 studies in PDs, including one RCT; all evaluated CBT interventions (Dobkin, Allen, & Menza, 2007; Dobkin et al., 2011; Dobkin et al., 2014) and all but one of these were delivered on a one-to-one basis. Three studies in MND included an RCT of individual psychotherapy (Averill, Kasarskis, & Segerstrom, 2013), a feasibility study of dignity therapy (Bentley, O'Connor, Kane, & Breen, 2014), and a case study of a CBT-based intervention (Pérez & Dapueto, 2014). Two case studies in HD reported a CBT (Silver, 2003) and a remotivation therapy (Sullivan, Bird, Alpay, & Cha, 2001) intervention respectively. Thus while CBT has been used to address mood and emotions in a range of PNCs (Fernie et al., 2015), other psychotherapeutic approaches, such as dignity therapy and remotivation therapy, have also been reported, although overall the evidence-base appears limited (Gould et al., 2015). There were no reports of psychotherapeutic interventions for people with FTD.

3.3. Education and self-management

There were 36 studies in MS reporting education, self-management and support groups conducted either in person, via telephone or online, including 15 RCTs and a number of

qualitative evaluations (Cecil, 2014; Regan et al., 2008). Four studies reported similar interventions for people with PD (Mulligan, Arps, Bancroft, Mountfort, & Polkinghorne, 2011) and one study surveyed 726 people about their experiences of using support groups (Dorsey et al., 2010). Two studies sought the views of people with MND attending a support group (Kasarkis, Elza, Bishop, & Spears, 1997; Regan et al., 2008). These surveys suggest that support groups may be accessed by significant numbers of people with some PNCs, but that outcomes are rarely evaluated. There were no reports of education, self-management or support groups for people with HD or FTD.

3.4. Support for caregivers

Only a small number of studies examined the effects of interventions for caregivers of people with PNCs. These carer interventions covered a mixture of progressive neurodegenerative disorders: FTD, HD, PDs and atypical early-onset dementias (Mioshi, McKinnon, Savage, O'Connor, & Hodges, 2013). Five studies reported on the effects of participating in caregiver support groups. One study investigated whether participants were in contact outside of group meetings (Dipple & Evans, 1998). One study assessed the effects of a positive emotion skill-building intervention (Dowling et al., 2014).

3.5 Methodological issues

Relevant studies were identified across all five conditions and all four types of intervention. However, the distribution across conditions and types of intervention was highly skewed with almost half of all studies, and 89% of all RCTs, relating to MS. There was a lack of randomised controlled trials in relation to the rarer PNCs. In many cases participant characteristics were insufficiently detailed; descriptions of the type and degree of cognitive impairment were often limited or even lacking altogether. Interventions implemented in group studies and RCTs were

often poorly-described, although in contrast the availability of numerous single-case designs meant that some interventions were clearly characterised. Interventions were also sometimes wrongly labelled with misleading names which did not properly reflect the nature of the intervention being reported. Reporting of case studies tended to focus on specific changes in performance relating to goals, needs or behaviours directly targeted in the intervention. In contrast, larger trials often reported only more distal measures such as quality of life or mood, covering areas where there may not necessarily be problems or impairments at baseline, or focused on measures of impairment such as neuropsychological tests which would not necessarily be expected to improve.

4. Discussion

This scoping review shows that there is a body of evidence across the five PNCs, despite the relative rarity of conditions such as FTD, HD and MND (Bilney, Morris, & Perry, 2003; Langenbahn et al., 2013), the lack of emphasis on cognitive and behavioural disability relative to other aspects of the condition in PD, MS and MND (Hindle et al., 2013), and the frequent exclusion from trials of participants with any degree of cognitive impairment or psychiatric co-morbidity. The review yielded relevant studies across all five conditions and all four types of intervention. However, the distribution across conditions and types of intervention was highly skewed with a large proportion of studies relating to MS, where the depth and quality includes Class 1 evidence (Chiaravalloti, Moore, Nikelshpur, & DeLuca, 2013). The evidence for cognitive rehabilitation in MS was examined in a previously-published Cochrane review (Rosti-Otajärvi & Hämäläinen, 2014). Thus, the need for further research is likely to be greater for the other four conditions.

The limited number of studies in PDs was somewhat surprising, given that PD itself is the most frequently-occurring PNC after Alzheimer's disease, cognitive impairment is widespread, and a high proportion of people living with PD will eventually develop dementia. This may have resulted in part from the time constraints that were imposed on the search period due to the very large numbers of records identified, but is likely also to reflect the lesser emphasis placed on cognitive as opposed to motor symptoms in PDs. The nature of FTD, HD and MND make it difficult to gather large enough sample sizes for single-centre intervention trials, so it is to be expected that the majority of reports would focus on single-case designs. For these rare conditions, multi-centre studies will be required to demonstrate effectiveness of interventions at group level.

With regard to types of intervention, the largest group of studies reported cognitive rehabilitation interventions. There were relatively few studies of psychological interventions or of self-management, education or support. The progressive nature of the cognitive and behavioural changes in FTD and HD, as well as debilitating motor aspects in HD, may limit the perceived relevance of these approaches, while people with PDs who develop significant cognitive impairment are likely to have been living with the condition for some time. Additionally, however, many professionals and services providing psychological interventions will not have a specific remit to provide services to these groups, and may lack knowledge about these disorders and experience difficulty in adapting the interventions to take account of motor problems and other condition-specific constraints. There is a need to develop a clear understanding about which interventions are most appropriate for people with each condition and how these may best be adapted to ensure suitability and acceptability. There were surprisingly few studies of support for caregivers of people with these conditions; possibly some caregivers are accessing support from charities focused on the specific conditions while

others may be accessing generic support for caregivers of people with dementia or a range of disabilities, but these approaches are not being evaluated systematically.

The findings highlight some of the key challenges inherent in attempting to synthesise evidence regarding psychosocial interventions, which must be addressed in order to provide definitive conclusions about efficacy and useful information for practitioners. These relate to study design, selection of participants, description of interventions, application of specific rehabilitation techniques, and choice of outcome measures. The lack of randomised controlled trials in relation to the rarer PNCs limits confidence in the robustness and generalisability of findings, especially as all the included studies reported some positive results, raising concerns about possible publication bias. Participants with PNCs are heterogeneous, and it is important to characterise the type and degree of cognitive impairment, and to take participant characteristics into account in order to provide information that is useful to practitioners. Similarly, clear descriptions of interventions are needed. It is important that interventions are correctly named and clearly described. Specific cognitive rehabilitation techniques and strategies could be applied in different ways across studies, making it especially important to derive appropriate guidance on how to incorporate these strategies into practice. In larger trials where evaluation focused on areas where participants might not have impairments or specific needs at baseline, or on measures of impairment which would not necessarily be expected to improve, the trial design could yield a negative outcome for a potentially-effective intervention. It is important to acknowledge that in a progressive condition an outcome of no change or slowed deterioration can indicate treatment effectiveness (Croot et al., 2009).

This review has a number of limitations. In undertaking the review, pragmatic considerations regarding budget and time available had to be balanced against achieving sufficient coverage

and breadth (Levac et al., 2010). More comprehensive searches and the ability to access papers that were not readily available would yield additional studies for inclusion; however, while we may not have accessed the full extent of the evidence, we believe that the scoping searches have provided a reasonably comprehensive picture of the nature and range of the evidence available. We have not undertaken any formal assessment of the quality of individual studies, but this is in line with the procedures adopted in other scoping reviews (Pham et al., 2014), where the aim is to gain an overview of the evidence rather than to make a detailed assessment of individual studies. We considered that given the preliminary nature of this review, an evaluation of study quality would not have added significantly to the work.

5. Conclusions

This scoping review has described the extent, nature and range of the research evidence relating to the effectiveness, experience and implementation of cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in PDs, MS, FTD, HD and MND. The limited range of studies for all conditions except MS suggests it will be important firstly to systematically synthesise the available evidence across these conditions, taking account of the methodological challenges inherent in this endeavour, and secondly to build on this by developing rigorous, well-designed studies to provide robust evidence about the effectiveness of CR and other psychological interventions in PDs, FTD, HD and MND. There is a need for evidence that can provide a basis for developing guidance to support the practice of health and social care professionals, and advice for people affected by these conditions and their carers, that could enhance the possibility of living well with cognitive disability.

Declaration of interest statement

DL reports: consultancy from Novartis, Bayer, TEVA, Biogen, Merck; speaker bureau for Almirall, TEVA, Biogen, Novartis, Bayer, Excemed; research grants from Novartis, Biogen, Bayer. All monies are paid to DL's university.

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Table 1. Cognitive, behavioural and emotional features that may arise in each of the five PNCs

Possible features:	PDs	MS	FTDs	HD	MND
Executive function impairment	√	√	√	√	√
Attention impairment	√		√	√	√
Information processing impairment	√	√	√	√	
Working memory impairment	√		√	√	√
Episodic memory impairment	√	√	√	√	√
Language and semantic impairment			√	√	√
Visuospatial perception impairment	√			√	
Delusions and hallucinations	√		√	√	√
Behavioural issues	√		√	√	√
Apathy	√	√	√	√	√
Depression and anxiety	√	√	√	√	√

Table 2. Search terms used in the scoping review

Population-related search terms

Huntington*

"Frontotemporal Dementia*" OR "Behavioural Variant Frontotemporal Dementia*" OR "Semantic Dementia*" OR "Progressive Non Fluent Aphasia*" OR "Progressive Non-Fluent Aphasia*" OR "Frontotemporal Logopenic Aphasia*" OR "bevFTD" OR "FTD"

"Motor Neuron" OR MND OR ALS OR "Amyotrophic Lateral Sclerosis" OR "Lou Gehrig*" OR "Progressive Bulbar Pals*" OR "Progressive Muscular Atroph*" OR "Primary Lateral Sclerosis" OR "Anterior Horn Cell*" OR "Mill* Syndrome*"

"Multiple Sclerosis" OR "Clinically Isolated Syndrome" OR "Radiologically Isolated Syndrome"

Parkinson* OR "Progressive Supranuclear Palsy" OR "Multiple System Atrophy" OR "Corticobasal Degeneration" OR "Lewy Body Dementia*"

"Progressive Supranuclear Palsy" OR "Multiple System Atrophy" OR "Corticobasal Degeneration" OR "Lewy Body Dementia*"

Intervention-related search terms

Intervention* OR Treatment* OR Therap* OR "Randomised Control* Trial*" OR "Intervention* Stud*" OR Rehabilitation OR Remediation OR Retraining OR "Single case*" OR "Support group*" OR Psychoeducation OR Education OR "Self-management" OR Advice

Table 3. Overview of studies included in the scoping review for each PND

(a) By research design

	MS (n=74)	PDs (n=19)	FTD (n=27)	HD (n=10)	MND (n=10)	Total (n=140)
RCT	31	3	1	0	0	35
Secondary analysis of RCT	11	1	0	0	2	14
Non-randomised group designs	22	10	3	5	2	42
Single case designs or case series	3	1	21	3	4	32
Qualitative evaluation	7	4	2	2	2	17

(b) By type

	MS (n=74)	PDs (n=19)	FTD (n=27)	HD (n=10)	MND (n=10)	Total (n=140)
Cognitive rehabilitation	21	9	21	7	5	63
Psychotherapy	17	5	1	2	3	28
Self-management	36	4	0	0	2	42
Carer interventions	0	1	5	1	0	7

Table 4. Studies included in the review

(a) Cognitive rehabilitation

Authors & Date	Design	Sample	Intervention	Aims	Key findings
Fronto-temporal dementia (FTD) including semantic dementia (SD) – 22 studies					
Bier et al. (2009)	Case study, pre-post-follow up	1 person with SD, 5 controls	Spaced retrieval	Explore formal semantic therapy	Better on trained items. Maintained at 5 weeks. No generalisation.
Bier et al. (2011)	Case study, pre-post- follow up	1 person with SD	Ecological approach CR	Explore effectiveness	Cooked more independently and initiating more cooking.
Bier, Brambati, et al. (2015)	Case study	1 person with SD	Ecological CR	Assess ability to learn new technologies	At 6-month follow-many technology functions still used.
Bier, Paquette, and Macoir (2015)	Case study	1 person with SD	CR	Assess baseline use of compensations and ability to learn new technologies	With an errorless learning approach, he learnt to effectively use 10 smartphone functions.
Dewar et al. (2009)	3 cases with HSE, 1 case with SD, pre-post	4 people with SD	Mnemonics and errorless learning for relearning semantic information	Explored relearning of semantic knowledge	SD improved on trained items. Maintained at 1 month. some generalisation
Dressel et al. (2010)	1 case, pre-post-follow up	1 person with SD	Phonological and semantic cueing hierarchies	Investigate use of treatment	Improved with both techniques at 2

					months but gains lost over time
Fick et al. (2014)	Case report	1 person with FTD	Behavioural intervention	Describe intervention for pacing + vocally disruptive behaviour	Vocally disruptive behaviour + pacing reduced
Frattali (2004)	Case study, pre-post- follow up	1 person with FTD	Errorless learning	Explore effectiveness	Improved on trained, no generalisation, gains lost at 3 months
Izzo, DiLorenzo, and Roth (1986)	Case study	1 person with Progressive Supranuclear Palsy	Therapeutic rehabilitation techniques.	Discuss the rehabilitation problems and management of the person.	Improvement in dysphagia and visual scanning.
Jefferies, Bott, Ehsan, and Ralph (2011)	Case study, between groups	1 person with SD, 8 controls	List recall and errorless learning	Explore whether and how can learn phonological information	Phonological learning improved
Jokel and Anderson (2012)	7 cases, pre-post	7 people with SD	Errorless, errorful, active and passive learning of naming and comprehension of treated words	Examine different combinations of training techniques	All training resulted in improvement. Errorless training was better maintained
Jokel et al. (2006)	Case study, pre-post-follow up.	1 person with SD	Home treatment programme (practising words of objects)	Explore a treatment programme. Designed jointly with participant.	Better on words with some retained semantic knowledge. Practice delayed progression of loss.
Jokel, Rochon, and Anderson (2010)	1 case, pre-post-follow up	1 person with SD	Computer delivered errorless learning	Explore effectiveness + feasibility	Good learning and 3 month retention

Newhart et al. (2009)	2 cases, pre-post (1 LPA, 1 SD)	1 person with SD, 1 person with logopaenic progressive aphasia	Cue hierarchy treatment for naming objects	Compare treatment across LPA and SD on lexical processing assessment	SD better with trained words but limited maintenance
O'Connor et al. (2016)	Case study	1 person with FTD-behavioural, 1 person with FTD-semantic	OT	Describe intervention and assess feasibility	Engagement in more activities, improvements in behaviour, reduced caregiver distress
Robinson et al. (2009)	Compared 2 cases with matched controls, pre- post-follow up	2 people with SD, 2 controls	Errorless learning and training	Explore training effectiveness (object naming, definition and use)	Improved naming, definitions and object use
Savage et al. (2013)	6 cases, pre-post	4 people with SD	Word retraining (repetitive practice of word-picture pairing)	Evaluate the success of training	More practice time improved maintenance (not much maintenance).
Savage, Piguet, and Hodges (2014)	Pre- and post-intervention comparison	5 people with SD	Online word training program	Examine whether gains in training generalise from picture naming to everyday settings	All 5 improved naming the trained pictures; 4 out of 5 improved on video description task
Savage et al. (2015)	Case series of single-subject experimental design	9 people with SD	Computer delivered rehearsal (individually tailored) of 75-100 words	Examine independent and assisted maintenance of object words	80% trained words retained at six months with independent or continuous revision

Snowden and Neary (2002)	Two case studies	2 people with SD	Repetition (some elements of errorless learning) of object names	Examine the impact of residual word/ object knowledge and contextual information on relearning	Partial semantic knowledge and experiential contextual information aided relearning
Snowden et al. (2012)	Case study, pre-post-follow up	1 person with PPA	Speech and language therapy	Case description	Improvement at 12 months but gains lost at 2 years
Suárez-González et al. (2015)	Case study. Compared standard and conceptual enrichment training	1 person with SD	Conceptual enrichment training	See whether generalisation improved if personalised semantic memories recruited	Better naming and generalisation with conceptual enrichment training
Huntington's disease (HD) – 7 studies					
Ciancarelli, Tozzi, and Carolei (2013)	Repeated measures	34 people with HD	Inpatient multifunctional neuro rehabilitation	Explore intervention effectiveness	Improvements lost at 3 month follow-up
Frich et al. (2014)	Qualitative interview (patients and caregivers) or focus groups (professionals) post-intervention	9 carers, 11 people with HD, 15 healthcare professionals	Group-based multidisciplinary residential rehabilitation (inc. training of cognitive function, assistive devices; individual counselling)	Assess feasibility (opinions of patients, caregivers, and professionals)	Patients and caregivers emphasised positive mental, physical, and social outcomes, professionals indicated intervention was feasible
Klasner and Yorkston (2001)	Case study	1 person with HD	SALT (linguistic and cognitive strategies taught to aid communicative participation)	Describe the use of linguistic and cognitive supplementation strategies	Improved frequency and satisfaction with communication and ADL completion

Mattern and Kane (2007)	Case study	1 person with HD	Occupational therapy-activity programme	Describe the case	Improved sense of purpose and developed friendships
Piira et al. (2013)	Repeated measures (3 admissions of 3 weeks over 1 year)	37 people with HD	Inpatient rehabilitation (physical exercise, social activities, group sessions)	Replicate Zinzi et al 2007 study	Improved gait, balance, physical QOL, anxiety and depression. No deterioration in cognition
Thompson et al. (2013)	Between groups	20 people with HD	MDT OT rehabilitation	Pilot the programme	Improvement in mobility, body strength, written errors and fat composition. Minor improvement cog + depression
Zinzi et al. (2007)	Repeated measures (3 week intensive, 3 times a year)	40 people with HD	Multicomponent-inpatient rehabilitation	Explore effectiveness	Improved motor performance, ADL performance and depression
Motor Neuron disease (MND) – 5 studies					
Cleary (2008)	Case study	1 person with MND	Behavioural – to decrease risk of pneumonia (e.g. instruction in good oral hygiene)	Describe intervention	Improved nutrition, energy, satisfaction, reduced distress and improved caregiver QOL
Kaiser et al. (2001)	Case study	2 people with MND	OT- computer device training	Evaluate the training technique (locked-in patients learned to use an EEG-based communication device)	Learnt to control cortical potentials without continuous feedback

Kübler et al. (2001)	Case study	2 people with MND	OT- computer device training	Describe and evaluate training (locked-in patients learned to use an EEG-based communication device)	Able to learn to control amplitude of slow cortical potentials
Neumann, Kübler, Kaiser, Hinterberger, and Birbaumer (2003)	Case study	1 person with MND	OT- computer device training (brain-computer communication)	To describe how a participant controlled EEG potentials	Used mental strategies to shift EEG potentials
Traynor et al. (2003)	Between groups-retrospective analysis	344 people with MND	MDT team care (neurologists, specialist nurses, occupational, speech therapists, pulmonologist, nutritionist, psychologist, social worker)	Evaluate outcomes on survival	MDT care increased survival time for bulbar onset patients (compared with general neurology clinic control)
Parkinsonian Disorders (PDs) – 8 studies					
Clarke et al. (2016)	Multi-centre RCT (PD REHAB Trial)	762 people with PD	People with limitations in ADL were randomised to physiotherapy and occupational therapy or no therapy	Evaluate efficacy	There were no significant improvements in the activities of daily living measure or the Parkinson Disease self-report measure in the therapy group.
Disbrow et al. (2012)	Between groups, 10-day training	30 people with PD, 21 controls	Computerised cognitive rehabilitation (designed to improve motor-related exec function)	Evaluate efficacy	Improvement in motor initiation and some generalisation to cognitive switching.

					Improvement on Trail Making B-A
Gil-Ruiz et al. (2013)	Case study	1 person with DLB	Environmental adaptation for management of the 'mirror sign' (inability to recognise one's reflection)	Case description	Improved DSM symptoms
Giovannetti, Seligman, Britnell, Brennan, and Libon (2015)	Between-groups	20 people with PDD, 20 people with AD, 20 people with PD	Goal cues (remind task goals/ improve performance on everyday tasks)	Assess feasibility	AD patients showed a significantly greater response to goal cues as compared with PD + dementia, the goal cues facilitated task completion, but did not promote error correction
Jain et al. (2004)	Pilot RCT	17 people with MSA	Individual OT	Identify feasibility and preliminary impact	Improved ADL functioning and health related QOL
Meek et al. (2010)	Article describes the process of designing and recording the intervention	19 people with PD	Individual OT to optimise independence	Detail the intervention	Mean number of visits 5.7 Found to be feasible and acceptable, informed larger phase 3 trial (PD REHAB)
Pretzer-Aboff, Galik, and Resnick (2011)	Repeated measures	21 people with PD	Individual function focused care intervention	Test feasibility and impact	Improved time spent exercising, disability, impairment, outcome

					expectations for exercise and QOL
Sturkenboom et al. (2013)	Process analysis	43 people with PD, 43 carers, 7 healthcare practitioners	Individual OT	Evaluate feasibility	Feasibility demonstrated but response rate 23%
Multiple sclerosis (MS) – 21 studies					
Allen, Longmore, and Goldstein (1995)	Repeated measures-case study	1 person with MS	Cognitive training (teaching mnemonic strategies to increase list learning + recall of names of faces)	Describe effect	Improved list learning, quicker name learning
Allen, Goldstein, Heyman, and Rondinelli (1998)	Single group pre- and post-training comparisons	10 people with MS	Computer-assisted teaching of imagery-based mnemonic strategies	Evaluate feasibility	Participants quickly learned the strategies but methods showed no significant effects on recall
Asano, Preissner, Duffy, Meixell, and Finlayson (2015)	Participants taken from an RCT (Finlayson et al., 2005) appears to report only the goal-setting group	81 people with MS	Goal-setting	Describe goals set and evaluate the extent to which participants keep goals over time	Around 50% of goals are achieved, the most common being IADL's and short-term goals
Birnboim and Miller (2004)	Single group pre- and post-training comparisons and 2 case studies	10 people with MS	Cognitive rehabilitation with metacognitive therapeutic approach	Explore efficacy	An overall improvement

			for executive function deficits		
Carr et al. (2014)	Pilot RCT	48 people with MS	Cognitive rehabilitation	Assess feasibility	Improved mood. No effect of memory programme on memory outcome measures
Chiaravalloti et al. (2013)	RCT (double-blind, placebo)	86 people with MS	Cognitive rehabilitation (modified Story Memory Technique, mSMT)	Treat learning impairment	Significantly improved learning and memory compared to placebo group
Chiaravalloti, Wylie, Leavitt, and Deluca (2012)	RCT (double-blind, placebo)	16 people with MS	Cognitive rehabilitation (modified Story Memory Technique, mSMT)	Investigate if the cognitive intervention created neural changes	Increased activation and improved list learning
Ernst et al. (2013)	Repeated measures	25 people with MS, 35 controls	Cognitive training (autobiographical memory)	Probe the programme	Improved autobiographical memory performance
Eyssen et al. (2013)	Cluster RCT	269 people with MS	Client-centred occupational therapy	Assess efficacy	No difference in primary outcome, negative findings in secondary outcomes, and positive findings in process outcomes
Fink et al. (2010)	Between groups	40 people with MS-RR	Cognitive training – attention/ exec function (RehaCom software)	Evaluate efficacy	Improvement in aspects of executive function, improved verbal learning

Gentry (2008)	Repeated measures	21 people with MS	Assistive Device training (personal digital assistants, e.g. calendar, alarms)	Evaluate impact on functional performance	Improved functional performance and satisfaction
Goverover et al. (2008)	Between groups	20 people with MS, 18 controls	Cognitive rehabilitation (self-generation to improve learning/ memory of meal preparation and managing finances).	Examine strategy utility	Self-generation improved learning and memory recall
Klaren, Hubbard, and Motl (2014)	Pilot RCT, pre- and post- trial questionnaire	70 people with MS	Behavioural intervention (to reduce sedentary behaviour)	Examine efficacy	Sitting time significantly reduced in the intervention group
Lexell, Flansbjer, and Lexell (2014)	Retrospective study with a pre-post design	43 people with MS	Individualised, goal-oriented interdisciplinary rehabilitation	Assess self-perceived performance and satisfaction with performance of daily activities	Self-perceived performance and satisfaction higher after rehabilitation program
Lincoln et al. (2002)	RCT (single blind)	240 people with MS	Cognitive rehabilitation (cognitive deficits identified with battery, then given tailored intervention. E.g. training in use of diaries)	Evaluate benefit cognitive assessment and intervention	No significant outcomes on mood, quality of life, subjective cognitive impairment, independence
Lincoln et al. (2003)	Secondary analysis of RCT treatment group (Lincoln et al., 2002)	29 people with MS	Cognitive rehabilitation (individualised)	Evaluate rehabilitation	Only a quarter of participants benefitted

Mäntynen et al. (2014)	RCT	102 people with MS-RR and subjective and objective attentional deficits	Cognitive rehabilitation (inc. computer WM training, psychoeducation, strategy learning, psych support)	Evaluate efficacy	No improvement in cognitive performance (processing speed, SDMT). Patients perceived reduction in cognitive deficits.
Rosti-Otajärvi, Mäntynen, Koivisto, Huhtala, and Hämäläinen (2013)	Secondary analysis of RCT (Mäntynen et al., 2014)	98 people with MS-RR	Neuropsychological rehabilitation (attention retraining, teaching compensatory strategies, psych support, homework).	Evaluate factors related to outcome.	More benefit for those w more severe attentional deficits (+male)
Salminen, Kanelisto, and Karhula (2014)	Qualitative analysis of focus group data	68 people with MS	Multi-professional group-based out-patient rehabilitation programs	Identify which components of rehabilitation are seen as helpful by people with MS	Diverse range of components identified
Shatil et al. (2010)	Between groups (unprompted, home-based, computerised training)	107 people with MS	Cognitive training (CogniFit Personal Coach)	Examine impact on cognitive performance	Improved general memory, visual memory, verbal-auditory working memory, LTM retrieval, naming, recall and processing speed
Stuifbergen et al. (2012)	RCT (single blind, waiting list control)	61 people with MS	Cognitive rehabilitation (Memory, Attention and Problem Solving	Refine and test the intervention	Improved self-efficacy and frequency of compensatory strategy use

			Skills for Persons with MS, MAPSS).		

(b) Psychological therapies for adjustment and mood

Authors & Date	Design	Sample	Intervention	Aims	Key findings
Fronto-temporal dementia (FTD) – 1 study					
Yokota et al. (2006)	Pre- and post-intervention comparisons	8 people with FTD	Group-Home Care	Evaluate impact of homelike physical and social environment in a care home.	Beneficial effects on behavioral and psychological symptoms of dementia, and psychotropic drug
Huntington's disease (HD) – 2 studies					
Silver (2003)	Repeated measures, case study	1 person with HD	CBT- individual	Describe key features of therapy and outcome	Improved anxiety and depression ratings
Sullivan et al. (2001)	Case studies	6 people with HD	Remotivation (group) therapy	Present case studies	Positive gains reported
Motor neuron disease (MND) – 3 studies					
Averill et al. (2013)	RCT	48 people with MND	Psychotherapy	Examine impact on psychological well-being	Improved psychological well-being but not maintained at six months
Bentley et al. (2014)	Repeated measures	29 people with MND	Psychotherapy (dignity therapy)	Assess feasibility, acceptance and potential effectiveness	No significant outcomes

Pérez and Dapueto (2014)	Case study	1 person with MND	Computer assisted (augmentative-alternative communication technology) Psychotherapy (based on CBT)	Describe how therapy was provided	Positive outcomes reported (improved communication with computer device, improved self-esteem, lower distress)
Parkinsonian Disorders (PDs) – 5 studies					
Dobkin et al. (2007)	Pilot repeated measures	15 people with PD	Individual CBT for depression in PD	Feasibility testing	
Dobkin et al. (2011)	RCT	80 people with PD	Individual CBT for depression in PD	First trial of CBT in PD	
Dobkin et al. (2014)	Additional analysis of RCT	80 people with PD	CBT	Describe neuropsychological outcomes	
Fitzpatrick, Simpson, and Smith (2010)	Qualitative (semi-structured interview)	12 people with PD	Mindfulness based cognitive therapy (MCBT)	Explore experiences of MCBT (8 week course)	Positive experiences/ gains reported
Jiménez-Murcia et al. (2012)	Between groups retrospective analysis (pilot)	60 people with PD	Individual CBT for pathological gambling in PD	Characterise therapy response	No differences in response between pathological gamblers with or without PD
Multiple sclerosis (MS) – 17 studies					
Askey-Jones, David, Silber, Shaw, and Chalder (2013)	Repeated measures (not blinded)	49 people with MS	CBT (individual) for common mental disorders in MS	Examine effectiveness	Reduced depression and anxiety but not maintained

Beckner, Howard, Vella, and Mohr (2010)	Secondary analysis of RCT (Mohr et al. 2005)	127 people with MS	CBT (telephone) for depression in MS	Examine whether social support is a mediator	Patients with higher social support responded better to CBT
Boeschoten et al. (2012)	Repeated measures (pilot)	44 people with MS	CBT (computerised) for depressive systems in MS	Examine feasibility and to examine outcome	Improved depression, problem solving skills and anxiety
Bombardier et al. (2013)	RCT	92 people with MS	Telephone-based physical activity counselling for major depression in MS	Examine effectiveness	Improved depression
Burns, Siddique, Fokuo, and Mohr (2010)	Secondary analysis of RCT (Mohr et al. 2005)	102 people with MS	CBT (telephone) for depression	Effects of comorbid anxiety on outcome	Comorbid fear reduced maintenance and comorbid GAD increased anxiety symptoms
Clancy, Drerup, and Sullivan (2015)	Single group pre- and post-intervention evaluation	11 people with MS	CBT	Evaluate efficacy	Improvements in insomnia, fatigue, and depression, although symptoms persisted
Dennison, Moss-Morris, Yardley, Kirby, and Chalder (2013)	Qualitative interviews	30 people with MS	CBT (mixed format) for adjustment to MS	Gain insight into participant experience	Positive outcomes reported
Graziano, Calandri, Borghi, and Bonino (2014)	RCT	82 people with MS	CBT (group) for reducing depression and improving quality of life	Evaluate effectiveness	Improved QOL and (in men) psychological well being

Mohr, Classen, and Barrera (2004)	Clinical trial, between groups	63 people with MS-RR	CBT, supportive expressive group psychotherapy, or sertraline	Examined the effects of treatment for depression on social support	All treatment interventions alleviated depression and increased perceived social support, utilised social support, and satisfaction with support.
Mohr, Hart, and Goldberg (2003)	Pre- and post-intervention assessment	60 people with MS-RR	Individual CBT, group psychotherapy, or sertraline	Examine the effects of treatment for depression on fatigue	All treatment interventions reduced fatigue severity, which was associated with fewer symptoms of depression.
Mohr et al. (2005)	RCT + 12 month follow-up	127 people with MS	CBT (telephone) and supportive emotion-focused therapy (telephone) for depression in MS	Evaluate efficacy for attention and nonspecific therapy effects	Significant improvement in depression measures and positive affect
Mohr, Hart, and Vella (2007)	Additional analysis of RCT (Mohr et al., 2005)	127 people with MS	CBT (telephone) and supportive emotion-focused therapy (telephone) for depression in MS	Evaluate effects on disability and fatigue	CBT superior in reducing disability and fatigue, depression
Nordin and Rorsman (2012)	Pilot RCT.	21 people with MS	Acceptance and commitment therapy (group)/ relaxation therapy (group) for MS with depression/ anxiety	Evaluate effectiveness	At 3 month follow up, relaxation training group had improvement in anxiety, acceptance and commitment therapy group showed

					improvement in self-rated acceptance
Rigby, Thornton, and Young (2008)	RCT assessing outcomes at five points over a one year follow up	138 people with MS	CBT (group), educational material (booklet), or educational material (booklet) + non-structured social discussion	Document mood, self-efficacy, and resiliency following group CBT and to examine whether benefits were greater than those derived from provision of education or group social interaction.	CBT improved self-effica and resiliency, and reduce anxiety, in comparison wi educational booklet intervention (but no significant difference). Al no difference between educational book and educational book + social discussion
Sheppard, Forsyth, Hickling, and Bianchi (2010)	Single group, pre- and post-assessment + 3 follow up	15 people with MS	Acceptance and commitment therapy	Investigate efficacy	Significant improvement in depression, thought suppression, impact of pain on behaviour, and QOL, but no change in the experience of physical symptoms and mindfulness practice.
Thomas et al. (2013)	Multicentre RCT (not blinded)	146 people with MS	CBT (group) for fatigue management	Effectiveness	Improved fatigue, severity and self-efficacy
van Kessel et al. (2008)	RCT	72 people with MS	CBT or relaxation training	Assess efficacy	CBT group reported significant reductions in fatigue, but there was no difference in stress, mood, or fatigue related impairment.

(c) Education and self-management

Authors & Date	Design	Sample	Intervention	Aims	Key findings
Motor neuron disease (MND) – 2 studies					
Kasarkis et al. (1997)	Survey	Approximately 100–130 people with MND attended at least one session	Informational support group using interactive video format	Describe the approach	High degree of user satisfaction and proficiency in using interactive video
Regan et al. (2008)	Survey	15 people with MND	Education and support group	Six month pilot of the programme	Positive feedback
Parkinsonian Disorders (PDs) – 4 studies					
A'Campo, Spliethoff-Kamminga, Macht, Roos, and Consortium (2010)	Repeated measures & feedback	64 people with PD, 46 carers	PEPP patient education	Evaluate caregiver impact	Improved burden (PD & caregiver)
A'Campo, Spliethoff-Kamminga, and Roos (2011)	Secondary analysis of A'Campo et al. (2010), standardised patient education programme for patients with Parkinson's disease and their carers	64 people with PD, 46 carers	PEPP group patient education	Identify treatment effect modifiers	No modifiers of PD outcomes Potential predictor of treatment benefit – caregiver having higher cog function
Dorsey et al. (2010)	Postal survey	726 people with PD	Support groups (patient)	Assess patient satisfaction with medical care and use of support groups	61% reported attending support group, 49% satisfied

Mulligan et al. (2011)	Single group post-intervention qualitative interview	8 people with PD	Self-management intervention	Assess feasibility	Improved knowledge and new strategies for living with PD and psychosocial benefits of meetings
Multiple sclerosis (MS) – 36 studies					
Barlow, Turner, Edwards, and Gilchrist (2009)	RCT	216 people with MS	Self-management (chronic disease self-management course, lay-led)	Determine effectiveness	Improved self-efficacy and physical health status
Barlow, Edwards, and Turner (2009)	Qualitative secondary analysis of Barlow et al. 2009	10 people with MS	Self-management	Explore experiences and value	Benefits perceived
Bombardier et al. (2008)	RCT (1 phone interview then 5 telephone counselling sessions)	130 people with MS	Telephone counselling for health promotion	Determine effectiveness	Improved health promotion behaviour, fatigue impact, mental health related QOL and self-reported physical activity
Cecil (2014)	Case study description	8 people with MS-Progressive	Support group (telephone) for home-bound patients (MS)	Consider first eight years of the group	Positive feedback
Dlugonski, Motl, and McAuley (2011)	Repeated measures	21 people with MS-RR	Self-management (internet) – increase physical activity	Examine efficacy using objective and self-report measures	Increased activity levels on objective and self-report measures
Dlugonski, Motl, Mohr, and Sandroff (2012)	RCT	45 people with MS-RR	Self-management (internet) – increase physical activity	Evaluate efficacy	Increased physical activity

Ehde et al. (2015)	Single centre RCT + 6 and 12 month follow up	163 people with MS	Self-management intervention (telephone delivered)	Evaluate efficacy	Significantly improved symptoms of fatigue, pain, depression, self-efficacy, activation, health related QOL, resilience, and affect.
Feys et al. (2013)	Uncontrolled interventional study with repeated measures	42 people with MS	Education day with theoretical and practical sessions to increase physical activity level	Evaluate effects	Enhanced physical activity behaviour in persons without perceived disability
Finlayson, Garcia, and Preissner (2008)	Qualitative	28 people with MS, 3 healthcare practitioners	Energy conservation (teleconference delivered) education program	Evaluation	Positive feedback but also limitations highlighted
Finlayson, Preissner, Cho, and Plow (2011)	RCT	190 people with MS	Energy conservation (teleconference-delivered fatigue management program)	Explore effectiveness and efficacy	Improved fatigue impact and aspects of HRQOL
Finlayson (2005)	Pilot repeated measures	190 people with MS	Energy conservation (group, teleconference)	Explore efficacy	Reduced fatigue impact and severity, better bodily pain and general health
Ghahari, Packer, and Passmore (2009)	Single group pre- and post-training comparisons	9 people with MS and 2 people with PD (no separate analysis)	Online fatigue self-management program	Develop program and evaluate effectiveness	Decreased fatigue
Knoop, van Kessel, and Moss-Morris (2012)	Secondary analysis of RCT (van Kessel et al. 2008)	70 people with MS	CBT- face to face and telephone for fatigue management	Assess mediators of effectiveness	Changing negative representations of fatigue crucial. CBT

					better than relaxation training (RT)
Mathiowetz, Matuska, and Murphy (2001)	Repeated measures-AB design	54 people with MS	Energy conservation course on fatigue impact, self-efficacy and QOL	Evaluate effectiveness	Improved fatigue impact, self-efficacy and aspects of QOL
Mathiowetz, Finlayson, Matuska, Chen, and Luo (2005)	RCT with immediate - delayed control group cross-over design	169 people with MS	Energy conservation course for people with MS, some with mild cognitive impairment	Assess the short-term efficacy and effectiveness	Decreased fatigue, increased self-efficacy and some aspects of quality of life
Mathiowetz, Matuska, Finlayson, Luo, and Chen (2007)	Follow-up secondary data analysis (see Mathiowetz et al. 2005)	169 people with MS	Energy conservation course	Report of 1-year follow-up analysis	Decreased fatigue and improved quality of life maintained up to 1 year post-intervention
Miller et al. (2011)	RCT	206 people with MS	Self-management prompts (web-based, participant generated)	Investigate effectiveness & feasibility	No group differences in favour of self-management prompts
Moss-Morris et al. (2012)	Pilot RCT	40 people with MS	Self-management (internet-based CBT self-management for MS, focus on fatigue)	Feasibility	Reduction in fatigue severity and impact. Improved anxiety and depression and increased QALYs
Motl and Dlugonski (2011)	Repeated measures (interrupted time series)	18 people with MS-RR	Self-management (internet) – increase physical activity	Examine effectiveness	Increased self-reported and objectively measured physical activity (small)
Motl, Dlugonski, Wójcicki,	Pilot RCT	54 people with MS-RR	Self-management (internet) – focus on physical activity	Examine effectiveness	Increased self-reported physical activity levels

McAuley, and Mohr (2011)					
Motl, Dlugonski, Pilutti, and Klaren (2015)	RCT, pre- and post-intervention assessment (Secondary analysis)	82 people with MS-RR	Behavioural intervention with goal-setting component to increase physical activity	Examine efficacy	Participants in the behavioural intervention group had significantly higher physical activity levels than controls. The efficacy of the intervention was moderated by MS type, disability status, and weight status.
Mulligan, Treharne, Hale, and Smith (2013)	Qualitative analysis of the feasibility trial data	27 people with MS	Combined self-help and professional help "Blue Prescription" to minimize physical and social barriers to participation	Establish content and resources required for delivery of the approach	Increased participation in community-based physical activity physical activity of their choice
Navipour et al. (2006)	Pre- and post-intervention comparisons	34 people with MS	Short-term self-managed graded exercise programme for various MS symptoms	Evaluates effects	Improved self-esteem and fatigue
Ng et al. (2013)	Pre- and post-intervention comparisons and follow-up assessment	129 people with MS	Wellness program of psychological and physiological evaluations, lectures and workshops	Determine efficacy	Improved self-efficacy and self-perceived health related outcomes, but no increase in physical activity

O'Hara, Cadbury, De Souza, and Ide (2002)	RCT	169 people with MS	Self-management (group/ individual)	Test efficacy	Improved mental health, fatigue and perceived need for assistance
Pilutti, Dlugonski, Sandroff, Klaren, and Motl (2014)	RCT Secondary analysis of data from RCT (see Sandroff et al., 2014)	82 people with MS-RR	Self-management (internet) - physical activity	Examine effectiveness on secondary outcomes	Improved fatigue severity and impact, anxiety and depression and physical activity level
Plow, Bethoux, McDaniel, McGlynn, and Marcus (2014)	Pilot RCT – randomly allocated two-group repeated measures design, delayed-treatment contact group was control	30 people with MS-RR	Patient education (customised pamphlets)	Explore effectiveness	Increased stage of change, social support, use of behaviour strategies
Plow, Bethoux, Mai, and Marcus (2014)	Additional secondary analysis of Plow et al 2014 (above)	30 people with MS-RR	Patient education (customised pamphlets)	Additional analysis	Improved physical activity, symptom severity, walking
Rietberg, van Wegen, Eyssen, and Kwakkel (2014)	RCT, pre- and post-trial assessment + 24 week follow up	48 people with MS	Multidisciplinary rehabilitation (received either physical therapy, OT, social work, or any combination of these)	Assess efficacy	No significant differences at 12 or 24 weeks follow up for fatigue, functional independence, impact on QOL or social participation
Sandroff et al. (2014)	Secondary analysis of RCT (Motl et al., 2011)	82 people with MS-RR	Self-management (internet) – increase	Secondary outcomes	Improved walking and improved cognitive

			physical activity in inactive MS		processing speed in mild MS
Shevil and Finlayson (2009)	Process evaluation (qualitative)	35 people with MS	Self-management (group)	Identify feasibility	Positive feedback related to group and course content
Shevil and Finlayson (2010)	Repeated measures	35 people with MS	Self-management	Pilot findings	Improved knowledge, strategy effectiveness and self-efficacy
Smith, Hale, Mulligan, and Treharne (2013)	Qualitative secondary analysis (see Mulligan et al. 2013)	27 people with MS	Combined self-help and professional help "Blue Prescription"	Investigate experience of participants	Therapy seen as supportive, motivating and enabling
Stuifbergen, Becker, Blozis, Timmerman, and Kullberg (2003)	RCT	57 people with MS	Self-management (group)	Determine efficacy	Improved self-efficacy and health behaviour at 8MFU. Immediate improvement in QOL
Stuifbergen, Becker, Timmerman, and Kullberg (2003)	Additional analysis of RCT	57 people with MS	Self-management (group)	Describe experience with goal attainment scaling	Increased goal attainment
Twomey and Robinson (2010)	Qualitative analysis	8 people with MS	Fatigue management programme	Examine the experience of participants	Experience described in positive terms

(d) Support for carers

Authors & Date	Design	Sample	Intervention	Aims	Key findings
Diehl, Mayer, Förstl, and Kurz (2003)	Single group post-intervention qualitative interview +6 month questionnaire follow-up	8 carers (FTD)	Caregiver support group	(1) To provide information, advice, and support to caregivers, (2) to establish needs of caregivers, (3) to encourage mutual support and develop coping strategies, (4) to evaluate the intervention	Reduced caregiver burden, enhanced coping strategies, establish new friends, rated programme as beneficial
Dowling et al. (2014)	Randomised control pilot study	24 carers (FTD)	One-on-one caregiver positive emotion skill-building intervention	Assess feasibility	Improved scores on measures of positive affect, negative affect, burden, and stress for intervention group.
McKinnon, O'Connor, Savage, Hodges, and Mioshi (2013)	Between groups	21 carers (FTD)	Caregiver support group	Qualitative evaluation of intervention	Increased functional responses to fictitious scenario
Mioshi et al. (2013)	Between groups	21 carers (FTD)	Caregiver support group	Verify utility of the intervention	Burden and reaction to behaviours reduced. No change in depression, stress and anxiety

O'Connell et al. (2014)	Post group feedback	10 carers (atypical early-onset dementia including FTD)	Caregiver support group	Develop and evaluate a support group for rural spouses of individuals with dementia	Positive feedback
Dipple and Evans (1998)	Qualitative - interview	27 (mix of HD carers and people with HD)	Support group	Describe the support network associated with the group	Infrequent contact outside group meetings
Shah et al. (2015)	Single group pre- and post- intervention questionnaires and post-interview	7 carers (PD)	Caregiver tele-support group	Assess feasibility	No significant findings, but scores on Geriatric Depression Scale decreased from 4.2 to 3.0

Key: CONDITIONS: FTD = frontotemporal dementia, SD = semantic dementia, HD = Huntington's disease, PD = Parkinson's disease, MND = motor neurone disease, MS = multiple sclerosis, PPA = primary progressive aphasia, LBD = dementia with Lewy bodies, PDD = Parkinson's disease dementia, AD = Alzheimer's disease, MSA = multiple system atrophy, MS-RR = multiple sclerosis remitting relapsing subtype. DESIGN: RCT = randomised controlled trial. INTERVENTION: CBT = cognitive behavioural therapy.

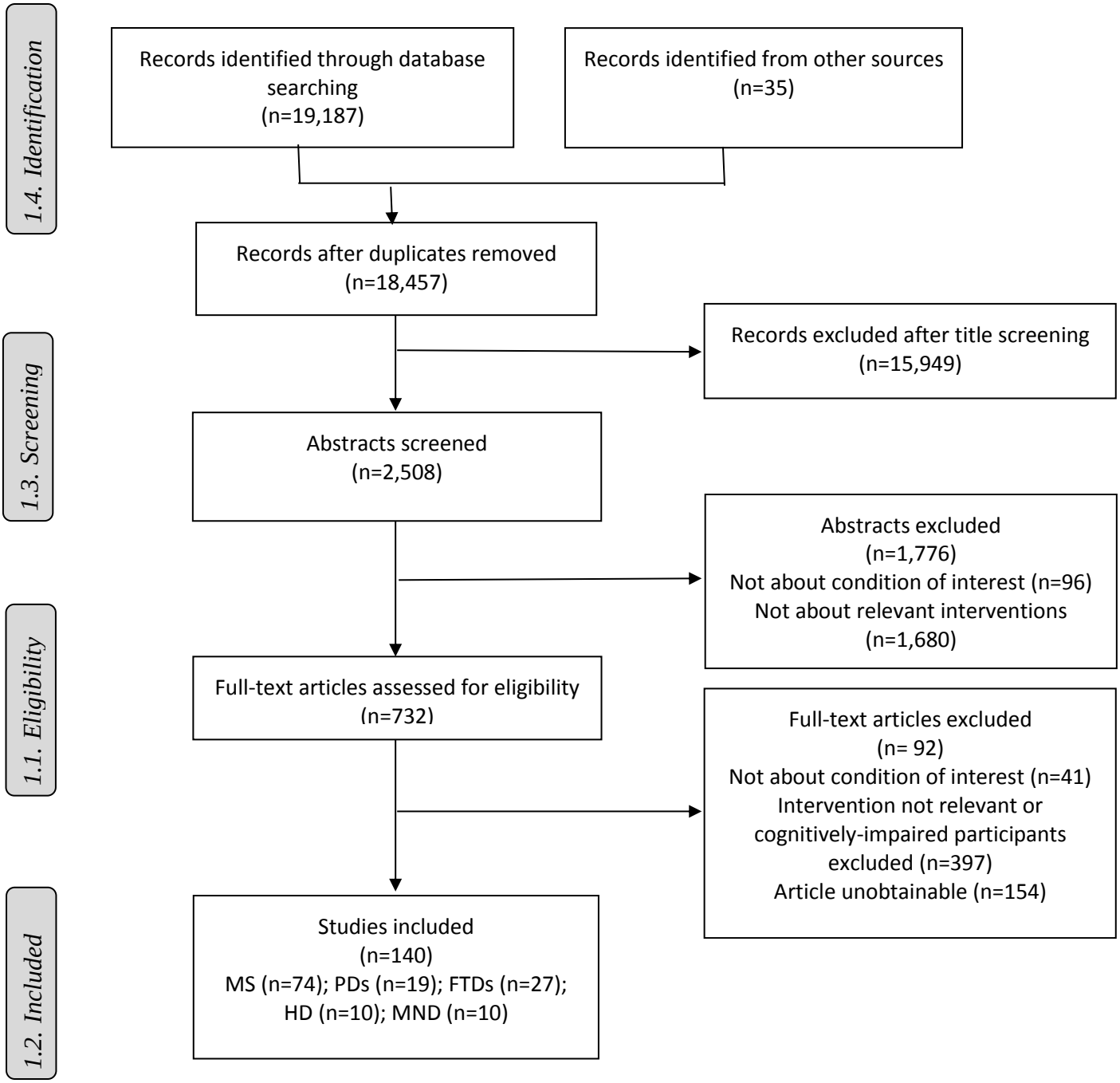

Figure 1. Flow chart illustrating the process of study selection