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EXTENDED EVIDENCE-BASED GUIDANCE ON PSYCHOLOGICAL INTERVENTIONS FOR PSYCHOLOGICAL DIFFICULTIES IN INDIVIDUALS WITH HUNTINGTON'S DISEASE, PARKINSON'S DISEASE, MOTOR NEURONE DISEASE, AND MULTIPLE SCLEROSIS

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Note on the extended version

The present report represents the extended version of the official guidance (British Psychological Society, 2021) produced and edited by Prof Jane Simpson, Dr Fiona Eccles, and Dr Nicolò Zarotti at Lancaster University as part of Minds & Movement, a national project aimed at producing the first UK guidance for psychological interventions in people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis.

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The official guidance (British Psychological Society, 2021) is available to download for free from the BPS website. Updated versions of the literature reviews carried out for the project have also been published elsewhere for Huntington's disease (Zarotti, Dale, et al., 2020), Parkinson's disease (Zarotti, Eccles, et al., 2020), and motor neurone disease (Zarotti, Mayberry, et al., 2020).

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INTRODUCTION

Aim and Focus

The aim of this guidance is to provide evidence-based recommendations for working psychologically for individuals living with the following four motor neurodegenerative conditions: Huntington's disease, Parkinson's disease, motor neurone disease and multiple sclerosis. By grouping these conditions together, we do not underestimate the considerable differences between them in terms of, for example, age of onset, average length of time living with the condition, symptom profile etc. However, they do share some important similarities in terms of the overarching frameworks in which psychological difficulties are most commonly understood and, unlike dementia which has its own specific pathway through the NHS, share some similarities in terms of care pathways. There are also significant challenges in providing psychological care and support for psychological difficulties for people with these conditions (see also Conclusion chapter).

The focus of this guidance is on interventions for specific psychological outcomes in the people experiencing the condition themselves. As a consequence, we have excluded interventions developed solely for family members and carers, as well as studies where the psychological outcomes of interest were not targeted primarily by the intervention. However, in cases of particular relevance or where no studies targeting outcomes primarily were available, some interventions where the outcomes were targeted secondarily are acknowledged in the Limitations sections. We have also focused on interventions that improve psychological well-being, but have excluded interventions that directly target cognitive function and have not looked at cognitive outcomes of interventions. While we do acknowledge the importance of such interventions, these were outside the scope of the current project. Finally, we have focused in the main on interventions for adults with one of these four neurological conditions. For Huntington's disease we have also included interventions for people who have received a

positive genetic test result meaning they will go on to develop the disease, but have not yet developed motor symptoms (which are currently required for a diagnosis), as individuals can still experience psychological difficulties in this period. However, we have excluded studies which focus on the test-taking period itself, including the decision whether to take the test, as this tends to be the remit of genetic counsellors in the UK and we viewed this also as outside the scope of the current project.

Target audience

This guidance has been written for all professionals, not just psychologists, who work with individuals with these conditions and who wish to have easy access to up to date guidance and recommendations. The challenges around how to resource access to these effective ways of working is addressed in the Conclusion section.

We focus here on the psychological approaches to address the identified psychological difficulties. For this reason, we do not include interventions which use medical approaches, such as antidepressant medications or surgical procedures (e.g., deep brain stimulation therapy in Parkinson's). We also acknowledge that many difficulties will be addressed by multi-disciplinary teams and, as such, the approaches listed here will not necessarily be the sole therapeutic approach. Indeed, for some issues, for example pain or fatigue, other members of the team such as occupational therapists, physiotherapists and/or neurologists may take the lead. Nonetheless, we hope this guidance is useful for informing such teams which psychological approaches may usefully contribute to multi-disciplinary care.

Theoretical framework

In adopting a psychological framework, we have not assumed that the difficulties are simply internally generated (i.e., via maladaptive cognitions). In this regard we wish to acknowledge the influence of the social model of disability (see Simpson & Thomas, 2015) which makes apparent the harmful psychological effects of living within a society which views disability as an individual construct rather than as a result of a society ill-equipped and sometimes poorly motivated to accommodate fully all those with physical impairments. This guidance is clearly not the only source of such a perspective and it is useful to note that a biopsychosocial framework is also being used by charities, such as in the Scottish Huntington's Association's national care framework (https://hdscotland.org/a-national-care-framework-for-huntingtons-disease/).

Methods and format

The format of this guidance has been to provide evidence of effectiveness for each neurodegenerative condition and, where studies allow, to categorise this per psychological outcome and, again where studies allow, per type of psychological intervention. To achieve this, a systematic review of the current literature was carried out. The specific methods are detailed in Appendix A, while the data extraction tables are available on the Minds & Movement webpage. Decisions regarding what to include as a target 'psychological' outcome were not always straight-forward, but we have erred on the side of inclusivity and so have included difficulties such as pain or fatigue, largely because these are often cause for referral to psychological services. We have not included psychological interventions designed to improve purely physical outcomes, although we do not doubt these can be effective. We have also been inclusive regarding evidence design, largely because, for some conditions, no

randomised controlled trials (often seen as the 'gold standard' of outcome evaluation designs) currently exist. This is particularly the case for Huntington's disease and to some extent motor neurone disease where very little research has been conducted. Although our search was thorough and regularly reviewed, we acknowledge that some studies may have been missed but we believe that any additions would not substantially change the conclusions of this guidance.

Notes on terminology

In writing this guidance we have been mindful of the BPS's position on the need not to rely on diagnostic frameworks such as the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013). We have used the terms 'depression' and 'anxiety' as these tend to be those used within the articles we have reviewed. However, by doing this we do not assume that such difficulties are always biologically mediated and have adopted a critical approach to studies which seem to overlook a multi-factorial causal perspective. While we do not rule out a biological contribution to psychological difficulties for some individuals, possibly via the same process that is responsible for the movement problems, we do not assume this. It is highly likely that in many cases (see also Garlovsky, Overton, & Simpson, 2016; Mistry & Simpson, 2013; Simpson, McMillan, Leroi, & Murray, 2015; Todd, Simpson, & Murray, 2010) such difficulties have emerged from psychological precipitating factors. Such factors have been generally overlooked in searching for causal explanations for psychological difficulties although recent research has started to offer alternative, psychologically-derived explanations (Horne-Thompson & Bolger, 2010; Simpson et al., 2019b; Simpson, McMillan, et al., 2013). As a result of this conceptual position, we have not used terms such as neuropsychiatric or 'non-motor symptoms' to describe psychological difficulties.

We have tried to keep acronyms to a minimum but some were necessary for expediency and ease of reading. The acronyms are all listed at the end of the document along with a glossary explaining the different therapies referred to in the text. The glossary also explains the use of terms for different study designs.

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HUNTINGTON'S DISEASE

Clinical description

Huntington's disease (HD) is a genetic neurodegenerative disease caused by an expansion of trinucleotide (cytosine-adenine-guanine or "CAG") repeats in the huntingtin gene (HTT), which is located on the short arm of chromosome four. The CAG repeats expansion results in the production of toxic mutant huntingtin protein (mHTT), leading to substantial damage to the basal ganglia, and in particular the corpus striatum (although there is incomplete penetrance in those whose CAG repeats are between 36-40). While people with HD (pwHD) typically experience motor impairments and cognitive deterioration, they can also experience significant psychological difficulties (Novak & Tabrizi, 2010). HD is hereditary with an autosomal-dominant mechanism, meaning that every affected individual has a 50% probability of transmitting the expanded gene to their children. Anyone who inherits the expanded gene will, at some stage, develop the disease. It used to be known as Huntington's chorea but in more recent times, the current and less stigmatising definition of 'Huntington's disease' is preferred.

HD is considered a rare condition, characterised by a prevalence of around 12.3 persons per 100,000 in the UK (Evans et al., 2013) and around 2.71 per 100,000 worldwide (Pringsheim et al., 2012). Many more people have been tested as positive for the gene expansion but are not included in these prevalence estimates which are based on the onset of symptoms (i.e., when diagnosis occurs). People with positive testing for HD without a formal diagnosis are usually referred to as 'gene carriers', 'presymptomatic' or 'premanifest' individuals (Dumas, van den Bogaard, Middelkoop, & Roos, 2013). For the purpose of this guidance, the terms 'premanifest' and 'manifest' will be used. Those with family history of the disease who have not undergone genetic testing are usually defined as 'at-risk' (Chisholm et al., 2013). The typical age of onset is 35 to 45 years, but juvenile onset (before 20 and as early as 2) can also

occur (F. O. O. Walker, 2007). Both men and women are affected by HD. No cure has been found so far and the mean life expectancy after the diagnosis is around 20 years (Folstein, 1989).

Genetic testing and diagnosis

Since the discovery of the gene responsible for HD in 1993, in the UK and many other countries predictive genetic testing is available for individuals aged 18 and over with a family history, allowing them to know if they carry the gene expansion even decades before the onset of symptoms. Nonetheless, the number of at-risk people who decide to undertake the predictive test ranges between 3% and 24% (Harper, Lim, & Craufurd, 2000; Laccone et al., 1999). In the UK in particular, the overall uptake of predictive testing is estimated between 15% and 26% (Quarrell & Rosser, 2014).

However, a positive genetic test does not constitute a formal diagnosis, as a clinical diagnosis of HD is based on the presence of neurological symptoms and signs. More specifically, the current mandatory clinical criteria for diagnosis are still motor symptoms, while the presence of cognitive and psychological changes, including emotional problems, is not necessary. This can present a considerable limitation for effective care, as such difficulties can arise much earlier than motor impairment, thus affecting premanifest individuals (Roos, 2010).

Motor signs and symptoms

Initially motor symptoms might present as restlessness or fidgeting which progress around diagnosis to more significant involuntary movements (chorea), and difficulties with coordination which begin to impact on activities of daily living. Eye movements may also change. PwHD may be unaware of these symptoms which might be more noticeable to partners or clinicians, although, understandably, some premanifest individuals can be

hypervigilant to any changes. As the disease progresses, body movements become fewer, slower, and more difficult to initiate, and normal daily activities such as eating, drinking and talking, along with general ambulation and voluntary movements, become progressively slow and arduous. Choking and falling both become a risk and speech becomes slurred. Finally, in the last stage individuals cannot leave their bed and need full nursing care. However, the trajectory and the type of symptoms is variable between individuals even in the same family (Roos, 2014; Roos, 2010; Walker, 2007a).

Cognitive impairments

Huntington's disease is associated with many cognitive impairments, which ultimately lead to dementia. Impairments can be expected in memory, psychomotor speed, executive functioning and, in later stages, language (Dumas et al., 2013). In premanifest individuals no significant issues are usually found in terms of linguistic and long-term memory functioning, but an early deterioration of executive processes and working memory may sometimes be observed (Dumas et al., 2012; You et al., 2014).

In addition, one of the most widely noted and investigated cognitive impairments involving people with manifest HD is difficulties in emotion recognition (Henley et al., 2012). In particular, an early significant deterioration of recognition of facial negative emotions, such as fear, disgust and anger, is often observed (Bates et al., 2014; Dumas et al., 2013; Henley et al., 2012; Johnson et al., 2007; Robotham et al., 2011), and other components such as emotional body language recognition can also be affected (Zarotti, Fletcher, et al., 2018). Investigations of the same kind of impairments involving people with premanifest HD report less consistent findings, as some studies have found specific impairments for disgust and negative emotions (Kipps et al., 2007; Milders et al., 2003), while others have reported no significant impairment at all (Labuschagne et al., 2013; Zarotti, Simpson, et al., 2018).

Psychological difficulties and well-being

Huntington's disease is also associated with a number of psychological difficulties. Among the most frequent are depression, mood extremes, 'irritability' and aggressiveness (but see Simpson et al., 2019a), anxiety, agitation, compulsions and apathy (Beglinger & Paulsen, 2008; Dale & van Duijn, 2015; Roos, 2010; van Duijn, Kingma, & van der Mast, 2007; van Duijn et al., 2014; Walker, 2007b). About 13% of people may also show obsessive-compulsive behaviours (van Duijn et al., 2014). Delusions and hallucinations are usually rarer (Roos, 2010; Walker, 2007b). An increased risk of suicide has often been observed in premanifest and manifest individuals (Hubers et al., 2012). Even more than the motor symptoms or pain (Ho & Hocaoglu, 2011; Ho, Gilbert, Mason, Goodman, & Barker, 2009; McCabe, Firth, & O'Connor, 2009; Underwood, Bonas, & Dale, 2017), depression and cognitive impairments have been reported to be a highly significant determinant of quality of life in pwHD (Banaszkiewicz et al., 2012). In addition, a recent UK survey reported how the top care priority among pwHD and their families was to receive expert help for the mental health component of the condition (Smith et al., 2015).

Since the results of a predictive genetic test for HD can only confirm whether an individual carries the expanded gene and will develop the disease, but not pinpoint when the onset will occur, a further psychologically challenging aspect of HD is the impact of predictive testing (Crozier et al., 2014). As shown by the generally low uptake estimates, most at-risk individuals prefer to remain uncertain about their status and, when undertaken, the test usually coincides with important life choices, such as marriage or pregnancy. Research on those who get tested and receive a positive result have reported inconsistent findings. Some participants show normal levels of psychological distress but also increased appreciation for life and relationships after one year (Broadstock et al., 2000; Duisterhof & Trijsburg, 2001), while

others regret taking the test and develop a negative view of their future characterised by reduced engagement in education, jobs, family, or long term life plans in general (Hagberg et al., 2011). In some cases a positive test result has been associated with suicidal thoughts (Wahlin, 2007). From a systemic perspective, pwHD may also report genetic discrimination, i.e., being treated unfairly or differently by others due to genetic differences, as opposed to physical ones (Bombard et al., 2011; Williams & Erwin, 2010). Moreover, family issues due to living with affected relatives and communicating the family history with the disease, especially when young children are involved, are often reported (Forrest Keenan et al., 2009).

Given the widespread and multiple difficulties the disease causes, further exacerbated by the familial nature of HD, this disease can have a devastating effect across the lifespan of pwHD and their systems of relationship (e.g., see Sobel, 2005). For instance, it is known that attachment difficulties in children with parents with HD can affect their later mental health (van der Meer et al., 2012), with childhood potentially affected by being parented by pwHD.

Conceptual framework

In contrast to the issue of predictive genetic testing, which has been traditionally characterised by a psychological approach in terms of how test results for HD might impact on people's lives and well-being, the currently dominant framework for understanding psychological difficulties experienced by pwHD is mainly neuropsychiatric (Simpson et al., 2019a). This affects not only the paradigm in which such research is conducted but also the perceptions of people with HD around their own condition. Indeed, as observed in a recent qualitative study, people with premanifest HD also tend to hold a more disease-based model of understanding distress, possibly due to the neuropsychiatric framework being conveyed in their interactions with many medical and clinical professionals (Theed et al., 2018). However, the same study also noted that people with the HD gene did express an interest in engaging

with psychological interventions, thus supporting the case for the development of an alternative, more psychologically-informed framework around their condition.

Psychological interventions

Anxiety

Currently, no trial studies have been carried out for the psychological management of anxiety with pwHD (Dale & van Duijn, 2015). One uncontrolled pretest-posttest study enrolled 29 manifest and 12 premanifest individuals in a Participant Education Program for HD (PEP-HD; A'Campo, Spliethoff-Kamminga, & Roos, 2012). The participants (alongside their caregivers, where applicable) undertook eight 2-weekly sessions of 90 minutes which consisted of psychoeducation with CBT components. The results showed significant improvements in anxiety for manifest participants, but not for the premanifest ones. No follow-up assessments were conducted; thus, it is unclear whether the improvements for manifest participants were maintained over time. Moreover, the study had a 25% dropout rate for manifest participants.

To date, only one single case study has explored the adoption of standard CBT with a person with premanifest HD (Silver, 2003), finding a decrease in anxiety from moderate to minimal, and benefits sustained at 6-month follow-up. However, the study did not report any information on the statistical significance of such changes. While current NICE guidelines for adults mainly recommend CBT for anxiety (NICE, 2011), further evidence is required to shed light on its efficacy and feasibility with people with premanifest and manifest HD.

Apathy

Apathy represents one of the most prevalent psychological difficulties in people with HD, affecting up to 70% of manifest individuals (Krishnamoorthy & Craufurd, 2011). It tends to

follow the physical and cognitive course of the disease (Fritz et al., 2018). However, no investigations have been carried out so far to address it specifically with a psychological intervention. Only one case series has explored constructs akin to apathy by adopting remotivation therapy (RmT) in pwHD (Sullivan, Bird, Alpay, & Cha, 2001) and reported improvements in interest, awareness, and overall participation at post-intervention. However, no quantitative data were provided to evidence such benefits.

In addition, the current conceptualisation and assessment of apathy in HD relies heavily on a neuropsychiatric framework which sees it solely as the result of the neurodegeneration process (Starkstein & Leentjens, 2008), with little to no attention focused on psychological reasons and affected individuals' understanding of the difficulty. However, preliminary evidence in a study with people with Parkinson's disease (Simpson, McMillan, Leroi, & Murray, 2015), found affected individuals' narratives of apathy were often characterised by more psychological explanations, such as saving energy to combat fatigue or avoiding activities which could represent a reminder of their physical changes. Similar adaptive reasons have been suggested for pwHD (Bachoud-Lévi et al., 2019). Thus, further exploration is currently warranted on alternative conceptualisations of apathy in pwHD.

Coping and resilience

Due to the diverse range of psychological difficulties associated with the condition, the successful operationalisation of coping strategies is considered of paramount importance for pwHD, as this plays a pivotal role in affected individuals' well-being (Kaptein et al., 2007). Moreover, the lack of effective coping measures has been shown to carry the risk of developing strategies characterised by avoidance, denial, and isolation (Lowit & van Teijlingen, 2005).

Nonetheless, only one uncontrolled pretest-posttest study has so far investigated the impact of an intervention on coping strategies in pwHD. A' Campo et al. (2012) adopted a psychoeducational programme with CBT components (PEP-HD) with both premanifest and manifest individuals and found significant improvements on specific components of coping such as seeking social support and reduced use of passive reactions for the latter. However, for premanifest participants, the benefits were limited to seeking social support. Further evidence is required to clarify whether coping interventions are effective for pwHD and whether they have a different effect on people with premanifest and manifest HD.

Depression

Depression is among the most common psychological difficulties reported by pwHD (Roos, 2010; Walker, 2007b), with over a third of individuals reporting difficulties (Slaughter et al., 2001). Moreover, low mood can often be observed in premanifest people well before a formal diagnosis is reached (Vaccarino et al., 2011), especially in relation to predictive testing (Hagberg et al., 2011), and an increased risk of suicide has been linked to both premanifest individuals (Hubers et al., 2012) and people at risk for HD (Arciniegas & Anderson, 2002).

To date, no RCT has been carried out to evaluate psychological interventions for depression in pwHD, and only preliminary data are available from smaller studies.

An uncontrolled pretest-posttest design assessing a psychoeducation programme in combination with CBT (PEP-HD) found significant improvements in mood for both manifest and premanifest individuals (A'Campo et al., 2012). However, these findings were based on a 100-point visual analogue scale (Mood-VAS), while the score comparison with a standardised measure (The Hospital Anxiety and Depression Scale, HADS; Zigmond & Snaith, 1983) showed no significant difference between pre- and post-intervention.

A case study (Silver, 2003) adopted nine sessions of CBT with a 44-year-old individual with premanifest HD and reported a clinical decrease in depression from moderate to minimal levels, and continuation of benefits at 6-month follow-up. However, no statistical data were reported for such changes. As for anxiety, CBT is one of the recommended approaches for depression in the general population (NICE, 2009a; SIGN, 2010b) and for those with chronic health problems (NICE, 2009b), but has not been well-researched for pwHD.

Fatigue

Despite some evidence suggesting that chronic fatigue can be a debilitating consequence of HD (Quinn & Busse, 2012), to the point of affecting how pwHD plan their daily life and social interactions (Zarotti, Simpson, et al., 2019), no studies have so far explored any interventions to address in this specific population. Moreover, unlike other motor neurodegenerative conditions (cf. MS), even the general literature around fatigue in HD appears to be severely limited.

Irritability, anger and aggression

Traditionally, irritability has been described as a tendency to react excessively to negative stimuli, consisting of an affective component (anger) as well as a behavioural one (aggression; Buss & Durkee, 1957; Caprara et al., 1985). The currently dominant neuropsychiatric approach considers irritability a very common symptom of HD, with prevalence estimates reaching over 70% in some cases (Van Duijn, 2010). With specific reference to pwHD, and in accordance with the dominant neuropsychiatric framework in the condition, irritability is generally considered a product of neurobiological changes in the basal ganglia and prefrontal areas rather than the psychological consequences of (often) living in a HD family and adjustment to the condition

(Craufurd & Snowden, 2014; Klöppel et al., 2010; Mega & Cummings, 1994; Tabrizi et al., 2009).

However, a recent review has questioned the validity of the current conceptualisation of irritability in pwHD, pointing out the inconsistency and general lack of a consensus in the literature over definitions and assessments methods (Simpson et al., 2019a). In particular, these results support the view of irritability as a multidimensional construct linked to other psychological difficulties such as depression and anxiety, rather than the result of neurodegeneration alone.

To date, no psychological intervention study has been carried out with pwHD to address the issue of irritability specifically. However, several interventions have proved to be effective to treat anger and aggression in the general population (for a review see Glancy & Saini, 2005), and these might be appropriate for those with HD who are considered to experience irritability.

A few case or small *N* studies have been published addressing aggression and other behaviours that challenge for individuals at later stages of HD (and who often had juvenile HD, hence the younger ages), who require nursing home and/or inpatient care. Behaviour support in combination with a pharmacological approach for one 32 year-old (Blass et al., 2001) and behaviour support in combination with sensory modulation for one 31 year old (Fisher & Brown, 2017) both reduced aggression. Sensory modulation[1] alone also reduced aggression for two other individuals aged 22 and 29 (Fisher & Brown, 2017). While not targeting

[1] Sensory modulation is arguably more likely to be delivered by occupational therapists and could be perceived as a more cognitive intervention but given the paucity of studies for HD is included for completeness alongside the other similar studies.

aggression specifically, another study with two pwHD suggested that it may be possible to teach behavioural relaxation (a simplified form of relaxation training) to reduce arousal. However, benefits were not retained once the intervention ceased (Fectau et al., 1987). Finally, one small RCT with 12 participants examined changes in mood and behaviour (on a combined scale) comparing relaxation (hearing music or stories) to multi-sensory stimulation and found no difference between groups (Leng et al., 2003). However, the groups differed at baseline and the study may have struggled to detect effects given the small sample. More methodologically rigorous studies are needed for aggression (Fisher, Sewell, Brown, & Churchyard, 2014) and more research is needed more widely for irritability.

Psychotic experiences

Psychotic experiences such as delusions and hallucinations are rare in pwHD (Craufurd, Thompson, & Snowden, 2001; Roos, 2010; Walker, 2007b), but may still occur at any stage of the disease (Anderson & Marder, 2001) and cause significant difficulties and concerns in both affected individuals and their relatives (Ding & Gadit, 2014). No psychological interventions have been evaluated so far to address psychotic experiences in pwHD. The current NICE (2014) and SIGN (2013) guidelines recommend CBT and family therapy for psychosis. While psychotic experiences in a mental health population and pwHD may differ, these approaches may act as a starting point for developing interventions for pwHD.

Access to psychological services

While little research exists for effective psychological interventions for pwHD, expert-based consensus clinical guidelines suggest non-pharmacological interventions (including psychological therapy) should be considered for psychological difficulties before pharmacological ones (Anderson et al., 2018). Similarly, international guidelines for HD

treatment (drawing on evidence for other neurodegenerative conditions) have suggested clinicians consider psychological approaches such as CBT as well as third wave cognitive therapies such as mindfulness and ACT for psychological difficulties (Bachoud-Lévi et al., 2019). However, the current access to psychological services for people with HD across the UK is patchy and unequal, with few psychologists with specific expertise in HD. People affected by HD are more likely to receive medication for their psychological difficulties and to be seen within a medical framework than a psychological one (Simpson et al., 2019a). Medical consultants often refer individuals to psychiatry rather than psychology, probably because of the lack of obvious care pathways. Where an individual's care lies with a neuropsychiatrist, then there is often a preference for this model to be used for all difficulties – psychological or motor. No survey of psychological provision currently exists for HD in the UK.

Few referrals are made to generic mental health services. The Improving Access to Psychological Therapies (IAPT) programme in England has recently widened to address long-term conditions but this has not extended to neurological conditions such as HD, and it is known that people with HD have trouble accessing generic psychological services or they can be unsuitable (The Neurological Alliance, 2017). This can lead to adverse consequences for pwHD who require specialist mental healthcare (The Neurological Alliance, 2017) and for physical, psychological and social needs to be considered together (SHA, 2019a).

Recently the National Care Framework for HD (SHA, 2019b) produced by the Scottish Huntington's Association, in conjunction with a range of stakeholders including pwHD and their families, has highlighted clinical psychology/neuropsychology to be among key services provided for pwHD. Other studies involving HD families have identified the importance for clinicians to have experience and knowledge of HD (Dawson, Kristjanson, Toye, & Flett, 2004). Such clinicians can work alongside the Huntington's Disease Association, Huntington's Disease

Association Northern Ireland and Scottish Huntington's Association who can provide help such as emotional support, family days, and education. Given the genetic nature of the condition, understanding the systemic factors at play is key (Maxted et al., 2014). Family therapy or other forms of systemic therapy are an important avenue to explore but currently no research has been conducted in the post test period.

This chapter has outlined that there is very limited research into how psychological approaches might benefit people with HD. It is of note that people with other motor neurodegenerative diseases mentioned in this document, where more research has been undertaken, have appeared to benefit from psychological interventions. Given the lack of psychological intervention studies among pwHD, the importance that families affected by HD place on receiving specialised mental health care and the psychological interventions that could be used to help this client-group, it is vital that there is more research undertaken to evaluate the application of psychological therapies for individuals with both pre-manifest and manifest HD.

Organisations and charities

Huntington Disease Association

Huntington Disease Association (which covers England and Wales) aims to improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights. For more details, see https://www.hda.org.uk/about-us.

Huntington Disease Association Northern Ireland

Huntington's Disease Association Northern Ireland provides support to individuals, families and carers living with Huntington's disease in Northern Ireland and also provides information,

advice and signposting for health and social care professionals. For more details, http://www.hdani.org.uk/cgi-bin/greeting?instanceID=1.

Scottish Huntington Association

Scottish Huntington's Association (SHA) has developed an extensive network of specialist services. For more information, see https://hdscotland.org/about-us/.

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PARKINSON'S DISEASE

Clinical description

Parkinson's disease (PD) is a chronic, progressive neurodegenerative condition caused in part by the death of dopaminergic neurons in the substantia nigra pars compacta. The resulting dopamine deficiency within the basal ganglia leads to disorders of movement, which are the hallmark of PD. The classic motor symptoms of PD are bradykinesia (slowness of movement), muscular rigidity, rest tremor and postural and gait impairment. These motor symptoms are heterogeneous in people with PD (pwPD) and clinical observations suggest two prominent subtypes: tremor dominant and non-tremor dominant (including akinetic rigid syndrome and postural instability gait disorder; Kalia & Lang, 2015). Other difficulties are also common and can include problems with cognition, affect and sleep as well as pain, gastrointestinal and autonomic symptoms (Chaudhuri & Schapira, 2006; Weintraub & Burn, 2011)

Motor symptoms usually appear after the age of 50 although disease onset can be at a younger age, then known as young onset Parkinson' disease (Willis et al., 2013). PD is the second most common neurodegenerative disease in older people (after Alzheimer's disease), affecting around one in 500 people in the UK (Mark, 2006). Worldwide prevalence estimates range from 1 to 418 per 100,000 and age specific prevalence increases until the ninth decade (Zhang & Roman, 1993), with the highest rates in Europe, North America and South America (Strickland & Bertoni, 2004; Von Campenhausen et al., 2005).

For many individuals the cause of PD is unclear and likely to result from a complex interplay between genes and environment. Gender is an established risk factor with male-to-female ratio around 3:2 and delayed onset in females is attributed to the neuroprotective effects of oestrogen (Martínez-Rumayor, Arrieta, Sotelo, & García, 2009; Miller & Cronin-Golomb, 2010). The biggest risk factor for PD is age, which reaches a peak after the age of 80 years (Driver et al., 2009). As a result, the diagnosis of PD is expected to increase by 50% by 2030

(Dorsey et al., 2007). Environmental risk factors have been argued to include pesticide exposure, previous head injury, rural living and well water drinking (Kalia & Lang, 2015). In terms of genetic contributions to PD, there is a suggested increased risk of PD associated with a familial history of PD or tremor. A number of linked genes have now been established with mutations in LRRK2 and parkin the most common cause of dominantly inherited and recessively inherited PD respectively (Corti et al., 2011).

Development of PD and diagnosis

It is now proposed that the onset of PD begins many years before diagnosis is made. For many this is evident through the onset of other difficulties, which can precede the onset of motor symptoms by decades (Postuma et al., 2012). These can include anosmia (loss of sense of smell), gastro-intestinal difficulties (e.g., constipation), as well as excessive day time sleepiness and rapid eye movement sleep behavioural disorder. This is often considered the preclinical or prodromal phase and the pathological processes that underpin the motor manifestations of PD are often argued to be underway during this time. Progression of PD is characterised by the onset and worsening of motor symptoms and other difficulties and diagnosis is usually made following the emergence of motor symptoms.

There is no definitive diagnostic test for PD, thus the diagnosis is made clinically and is based on the presence of cardinal parkinsonian motor features, associated and exclusionary symptoms and response to medication. Parkinson's disease is the most common form of Parkinsonism, which refers to the motor features of Parkinson's disease, but a number of secondary causes also exist. This means that differential diagnosis can be challenging early in the course of Parkinson's as there can be overlap with other diseases and syndromes (Gelb et al., 1999). Some of the differential diagnoses such as multiple system atrophy (MSA) and progressive supranuclear palsy (PSP) have a significantly worse prognosis and so this can be a

very uncertain time for people undergoing diagnosis, particularly when atypical features are present.

Management

Currently no cure or disease modifying treatment is available for PD. Thus, a continuous reduction in physical functioning is inevitable as the disease progresses (Mark, 2006; Weintraub & Burn, 2011). The mainstay of treatment for PD has been the alleviation of motor symptoms through drug treatments that increase the concentration of dopamine or directly stimulate dopamine receptors in the brain. Initially the symptoms of PD are typically well managed through medication, but as the disease progresses many complications begin to emerge that are often the result of long-term symptomatic treatment. This can include motor and non-motor fluctuations, dyskinesia and psychosis. As the disease advances it becomes less responsive to treatment and treatment resistant symptoms develop such as freezing of gait, balance difficulties, falls, dysphagia, incontinence and cognitive impairment. Considering that the life expectancy of pwPD is only slightly lower than that of the general population, this translates into many years of chronic illness and has a significant impact on pwPD and their families.

Psychological difficulties

PD is most commonly recognised as a motor disorder and, as a result, psychological difficulties (and other problems outside the motor ones) are often under-recognised by healthcare professionals (Barbosa, 2013). Yet in addition to motor symptoms, pwPD are often confronted by a range of psychological difficulties including depression, anxiety, cognitive impairment, apathy, impulse control behaviours, and other psychological problems, which may be treatment resistant. Indeed, psychological difficulties in PD are very common and can be as

disabling as motor symptoms (Goldman & Holden, 2014; Truong et al., 2008), with the severity of psychological difficulties a key predictor of health-related quality of life (Leroi et al., 2011; Soh et al., 2011).

Historically, our understanding of psychological difficulties in PD has been dominated by neurobiological conceptualisations (Brown & Jahanshahi, 1995). These assume that psychological difficulties in PD occur as a result of pathological physiological processes, such as changes in dopaminergic systems (Chaudhuri & Schapira, 2009). More recently, however, it has been recognised that the psychological difficulties in PD are likely caused by a combination of both neurobiological and psychological factors (Simpson, Lekwuwa, & Crawford, 2013; Weintraub & Burn, 2011).

Psychological distress can occur at any time throughout the course of PD, either acutely, continuously, intermittently, or transiently. This may include mood disturbance prior to diagnosis; psychological reactions to the initial diagnosis, as well as the changes experienced as the condition progresses; psychological disturbance caused by changes in neurotransmitter, inflammatory and neurotrophic factors; and the psychological side-effects of dopaminergic treatment (Even & Weintraub, 2012). In light of such complexity, multi-disciplinary team approaches are advocated to provide specialist assessment and treatment. Given the multiple physical symptoms experienced by pwPD it is likely that psychological interventions might also work best when physical symptoms are optimally controlled (although this is not to imply this relationship is one directional), hence the need for joined-up MDT involvement.

Cognitive impairment

Cognitive impairment in PD is significant and constitutes an important clinical aspect of the disease (Janvin et al., 2003). The trajectory of cognitive impairment is variable along the course of the disease, but could be conceptualised as progressing from mild deficits in selected domains of cognition, evolving to mild cognitive impairment (PD-MCI; Litvan et al., 2012) through to dementia (PDD; Emre et al., 2007). Cognitive changes can be present at the earliest stages of the disease with deficits in executive functioning most commonly observed (Foltynie et al., 2004), which include alterations in working memory, cognitive flexibility, planning and attention (Muslimovic et al., 2005). Deficits in immediate memory and processing speed are also observed (Foltynie et al., 2004), suggesting a frontal-subcortical syndrome that relates to the to the progressive dopaminergic depletion in the early stage of the disease (Nandhagopal et al., 2011). Progression of cognitive dysfunction to PD-MCI and PDD is a multifactorial process involving pathological and neurochemical changes (Pagonabarraga & Kulisevsky, 2012).

Psychological interventions for pwPD

Anxiety

Anxiety is a common and often under recognised difficulty in pwPD, estimated to affect around 69% of individuals (Richard, 2005). Along with falls, it is one of two difficulties in pwPD that caregivers rate most frequently as impacting upon their quality of life (Deane et al., 2015). It is associated with care dependency, poor work and social function, and reduced health related outcomes (Schrag et al., 2000). It has also been shown to interact with the motor symptoms such as tremor and gait disturbance (Burn et al., 2012).

CBT

Twelve studies have been carried out to evaluate cognitive behavioural therapy (CBT) for anxiety in pwPD. Of these, four were RCTs (Calleo et al., 2015; Lawson et al., 2013; Troeung et al., 2014; Wuthrich & Rapee, 2019), one a quasi-experiment (Berardelli et al., 2018), two uncontrolled pretest-posttest designs (Berardelli et al., 2015; Dissanayaka et al., 2017), one a multiple baseline single case experimental design (Reynolds et al., 2019), two case series (Feeney et al., 2005), and two single cases (Mohlman et al., 2010; Richardson & Marshall, 2012).

The results from the RCTs and one quasi-experiment are mixed. Interventions had manualised content, mainly focusing on skill acquisition, with only one study offering elective sessions alongside core components (Calleo et al., 2015). Content and delivery of interventions were adapted for the PD population, most commonly simplifying interventions to take into account potential cognitive difficulties. Only one study included caregivers as part of the study, offering stress management techniques (Wuthrich & Rapee, 2019). CBT was delivered weekly over eight to 12 sessions, with the length of sessions ranging from 30 minutes (Calleo et al., 2015) to 45 minutes (Wuthrich & Rapee, 2019) for individual sessions and 90 minutes (Berardelli et al., 2018) to 120 minutes (Troeung et al., 2014) for group therapy.

Both Calleo et al. (2015) and Wuthrich and Rapee (2019) administered CBT individually either in person and via telephone (Calleo et al., 2015) or solely via telephone (Wuthrich & Rapee (2019). Both found no statistically significant improvements in anxiety when compared to waitlist control or enhanced care, but both had small sample sizes so findings may not be reliable and need investigating in larger samples.

Troeung et al. (2014) compared a group CBT treatment consisting of psychoeducation, relaxation training, cognitive therapy, problem solving and behavioural activation to controls

placed on a wait list. The results showed significant and large effects for anxiety at post-intervention, as well as at 1-month and 6-month follow-ups, although again due to the small sample size results may not be generalisable.

Lawson et al. (2013) developed a bibliotherapy programme consisting of a CBT-based self-help guided reading resource ("What? Me Worry!?!") combined with telephone support at two-week intervals, and evaluated it in an RCT against simple information about worry. Significant reductions were seen in the intervention group for the primary outcome of worry, although differences in final outcomes between the intervention and control groups were not observed.

Finally, Berardelli et al. (2018) compared group CBT to psychoeducation in a quasi-experiment and found significant improvements in anxiety for the CBT group post-intervention.

The non-experimental studies using CBT as the primary intervention have reported mostly positive findings. Berardelli et al. (2015) evaluated group CBT for 12 weeks with an uncontrolled pretest-posttest design and found significant improvements in anxiety post-intervention. A similarly designed study by Dissanayaka et al. (2017) found that improvements were maintained at three and six months. This was consistent with the findings of all the case studies (Mohlman et al., 2010; Richardson & Marshall, 2012; Veazey et al., 2009) except for Feeney et al. (2005), who did not observe any significant improvements for anxiety. Similar positive findings were also reported by Reynolds et al. (2019), who adopted a multiple baseline single case experimental design to evaluate CBT administered either by videoconferencing or in person. They found significant reductions in anxiety in seven out of nine participants post-treatment, with changes functionally related to treatment and most improvements maintained at 6-week follow-up.

Mindfulness

The use of mindfulness-based interventions to address anxiety in Parkinson's disease has been evaluated by two RCTs (Kwok et al., 2019; Rodgers et al., 2019) and two uncontrolled pretest-posttest studies (Birtwell, Dubrow-Marshall, Dubrow-Marshall, Duerden, & Dunn, 2017; Dissanayaka et al., 2016). Most reported an improvement in anxiety post-intervention, with effects maintained at 2-month (Birtwell et al., 2017), 3-month (Kwok et al., 2019), and 6-month follow-ups (Dissanakaya et al., 2016). However, Rodgers et al.'s RCT (2019) did not find any significant improvements compared to waitlist controls. There was some variation in delivery and content with two studies using the same protocol based on six two-hour sessions of mindfulness-based cognitive interventions (MBCT; Dissanayaka et al., 2016; Rodgers et al., 2019), one adopting a mindfulness-based stress reduction (MBSR) course (Birtwell et al., 2017), and one using an adapted yoga intervention that included components of mindfulness across eight 90-minute sessions (Kwok et al., 2019). Certain adaptations were made to account for the PD population, including omitting certain exercise involving motor or sensory components, shortening sessions and meditation practices, simplifying language and using more relevant metaphors.

Relaxation

Although often included as part of CBT protocols, relaxation has been explored as a standalone intervention for anxiety in pwPD. Two single case studies report reductions in objective (therapist-rated) and subjective measures of anxiety post-treatment for social anxiety (Lundervold et al., 2013) and generalised anxiety (Lundervold et al., 2008). Both studies employed behavioural relaxation techniques that taught 10 overt relaxed behaviours, but one study also combined imagery and coping techniques (Lundervold et al., 2008).

Sessions were short, lasting around 15 to 20 minutes and required daily practice, and both studies reported the intervention as acceptable to participants.

Other approaches

Sproesser et al. (2010) carried out an RCT to evaluate a psychotherapy intervention based on psychodrama methods, such as role-playing of situations of daily life and discussions of interactions. They found significant improvements in anxiety post-intervention compared to controls who received no psychological treatment.

Finally, a single case design adopted eye movement desensitization and reprocessing (EMDR) to address trauma symptoms in a person with PDD (Ahmed et al., 2018), finding no change for anxiety.

Apathy

Apathy has been defined as a lack of interest, emotion and motivation, which may be part of a wider behavioural range of 'motivation' difficulties (Leroi et al., 2012; Pontone et al., 2006). It is relatively common, affecting up to 40% of all pwPD (den Brok et al., 2015), and has been shown to negatively impact quality of life as well as increase caregiver burden (Leroi et al., 2011, 2012; Van Reekum et al., 2005). Apathy is closely linked to the development of cognitive impairment in pwPD (Martin, McDonald, Allsop, Diggle, & Leroi, 2019).

Despite this, only two studies to date have sought to examine the use of psychological therapies in reducing apathy in pwPD (Berardelli et al., 2018; Butterfield et al., 2017).

Butterfield et al. (2017) adopted an uncontrolled pretest-posttest design and found that six weeks of activity scheduling and monitoring significantly reduced apathy and depression in 27 participants with PD, and these gains were maintained at one-month follow-up. The targets

for the activity scheduling were first agreed in a two-hour in person planning session, and then supported by automated reminders and short weekly telephone calls.

Berardelli et al. (2018), using an RCT comparing group CBT to psychoeducation in a sample of 18 pwPD, found significant improvements in apathy for the CBT group post-intervention, while no significant improvements were observed for the psychoeducation group.

Depression

Up to half of all people living with PD are thought to be affected by low mood and/or depression (Reijnders et al., 2008). Depression in PD is associated with faster disease progression, higher levels of dependency and greater caregiver burden (Chen & Marsh, 2014). Depression in PD is usually assessed using generic measures of mood (e.g., Hospital Anxiety and Depression Scale, Zigmond & Snaith, 1983; Hamilton Depression Rating Scale, Hamilton, 1960; Beck Depression Inventory, Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Zung Self-Rating Depression Scale, Zung & Durham, 1964), or those aimed at older people (Geriatric Depression Scale, Yesavage et al., 1982). However, all of these measures assess symptoms that overlap between depression and parkinsonism, and therefore adjusted cut-off scores may be useful (Schrag et al., 2007). There is now good evidence that psychological therapies are useful for reducing symptoms of depression, even in those where antidepressants have not been useful, with the majority of studies using CBT techniques.

CBT

Evidence from three RCTs with differing *N* has shown that CBT is superior to usual care and even enhanced usual care for improving low mood in PD. These improvements were documented when CBT had been delivered either individually (Dobkin et al., 2011; Wuthrich & Rapee, 2019) or in a group (Troeung et al., 2014). All of these studies enrolled participants

who met clinical criteria for depression at baseline, using clinically validated scales, and those who reported effect sizes described at least medium-sized effects (Dobkin et al., 2011; Wuthrich & Rapee, 2019), although two had small samples meaning their findings may not be generalisable (Wuthrich & Rappee, 2019; Troeung et al,. 2014). Two other small RCTs have not found CBT to be superior to clinical psychoeducation and/or monitoring, either at end of treatment (Veazey et al., 2009), or at 1-month follow-up (Calleo et al., 2015). However, these were both limited by small participant numbers and relatively high attrition rates. The adopted forms of CBT usually consisted of 8 – 12 sessions, delivered weekly by phone (Wuthrich & Rapee, 2019) or face to face (Dobkin et al., 2011; Troeung et al., 2014). All of these studies adapted the content and delivery of the therapy to the needs of the PD population, placing greater emphasis upon behavioural and behavioural management techniques. Most also incorporated caregivers into the therapy, offering stress management techniques to the caregivers as part of the pwPD weekly session (Wuthrich & Rapee, 2019), or several sessions of psychoeducation (Dobkin et al., 2011). The group intervention struggled with recruitment (Troeung et al., 2014).

A number of other studies which adopted observational and/or uncontrolled experimental methods have also reported CBT to be useful for improving low mood in pwPD. These included quasi-experiments (Berardelli et al., 2018; Tiihonen, Lankinen, & Viemerö, 2012), uncontrolled pretest-posttest designs (Berardelli et al., 2015; Dobkin, 2014; Dobkin, Allen, & Menza, 2007; Dobkin, Interian, Durland, Gara, & Menza, 2018; Dobkin et al., 2011; Shinmei et al., 2016), single cases (Ahmed et al., 2018; Richardson & Marshall, 2012), case series (Cole & Vaughan, 2005; Dobkin, Allen, & Menza, 2006; Feeney, Egan, & Gasson, 2005), and a multiple baseline single case experimental design (Reynolds et al., 2019). The improvements in mood were also maintained at one-month (Dobkin, Allen & Menza, 2006, 2014; Feeney et al., 2005) and three-month (Shinmei et al., 2016) follow-ups.

Mindfulness

Six studies have evaluated the use of mindfulness techniques for improving low mood in pwPD, of which three were RCTs (Kwok et al., 2019; Pickut et al., 2015; Rodgers et al., 2019) and three were uncontrolled pretest-posttest studies (Birtwell et al., 2017; Cash, Ekouevi, Kilbourn, & Lageman, 2015; Dissanayaka et al., 2016). Studies using MBCT or MBSR have reported significant improvements in depression (Cash et al., 2015; Rodgers et al., 2019), with large effect sizes. These findings are consistent with those from a qualitative investigation, which reported that pwPD, who participated in a 8-week MCBT course, found MCBT to be an acceptable form of group intervention (Fitzpatrick et al., 2010). Kwok et al. (2019) also found significant improvements following mindfulness-based yoga, delivered in a group format, which were maintained at three-month follow-up. However, it should be noted that, unlike the CBT studies, two of these studies excluded pwPDs with major depression (Cash et al., 2015; Kwok et al., 2019), while Rodgers and colleagues (2019) used no depression inclusion criteria and found that the group average depression score was in the normal range.

Pickut et al. (2015), Dissanayaka et al. (2016), and Birtwell et al. (2017) all administered a form of MBSR intervention, reporting mixed results. The latter found significant improvements both post-intervention and at follow-up, as well as high participant satisfaction on the parallel qualitative component of the study. However, Dissanayaka et al. (2016) found significant improvements post-intervention only (likely due to attrition at follow-up), while Pickut et al. (2015) did not observe any significant effect of the intervention on depression at all, finding only an increase in general levels of mindfulness, but there was no requirement for participants to have clinical levels of depression at baseline.

Psychoeducation

Two studies have examined the use of PD-specific psychoeducation programmes to manage daily aspects of PD (e.g., diet and movement) as well as improve low mood, one of which was an RCT (Guo et al., 2009) and one an uncontrolled pretest-posttest design (Macht et al., 2007).

Guo et al. (2009) found that three hour-long lectures and 24 subsequent 30-minute individual sessions did not lead to an objective improvement in mood when compared to a waiting list control group. However, they did not recruit pwPD who had clinically-significantly levels of depression and the intervention group's average depression score was in the normal range, making reductions harder to evidence

Macht et al. (2007) developed a "patient education programme based on information sessions, self-monitoring, health promotion, stress management, and management of depressive moods and anxiety" consisting of eight 90-minute sessions. This was then formally evaluated across seven European countries (Spain, Finland, Italy, The Netherlands, United Kingdom, Estonia, Germany) with a total sample of 151 participants. The results found no significant improvements in self-rated depression.

Other approaches

Sproesser et al. (2010) used an RCT to evaluate a form of group psychotherapy consisting of psychodrama techniques, such as role-playing. They administered 12 90-minute psychodrama group sessions every fortnight and compared them to a waiting list control group. The results showed significant improvements in depression for the therapy group at post-intervention.

Ahmed et al. (2018) reported a case study in which EMDR therapy was used with a woman with PDD. No improvements on depression were observed following six sessions of therapy or at 9-month follow-up. Moreover, some difficulties in administering EMDR were reported,

as eye movements were slowed. However, this study is notable for being the only study that included a pwPD with dementia. Most studies to improve mood have excluded pwPD with any evidence of cognitive impairment, but this study illustrated that psychological therapies can be both required and received well by people with PDD, even if this study did not lead to significant improvement in mood symptoms.

Impulse control disorders

Impulse control disorders (ICDs) describe a range of behavioural changes, which may include pathological gambling, compulsive sexuality, binge eating, compulsive shopping, and the abuse of dopamine replacement therapy (Leroi et al., 2012; Pontone et al., 2006). They can occur in up to 14% of pwPD (Graeme et al., 2013) and have a negative effect upon quality of life for pwPD and their caregivers (Leroi et al., 2011, 2012; Van Reekum et al., 2005). Nevertheless, to date only two studies have evaluated the effectiveness of a psychological therapy for ICDs in pwPD (Jiménez-Murcia et al., 2012; Okai et al., 2013), even though the development of ICDs has a clear psychological component (Delaney, Leroi, et al., 2012; Delaney, Simpson, et al., 2012).

The larger of the two, an RCT led by Okai et al. (2013), randomised 45 pwPD with ICDs, to either an intervention involving 12 sessions of face-to-face CBT or a waitlist. The CBT sessions were mostly offered at home and comprised a number of components, including psychoeducation with the ICD as the primary focus, motivational interviewing based on the change cycle, collaborative problem solving, behaviour monitoring, and pleasant activity scheduling. Caregiver support, psychoeducation regarding the symptoms, and collaborative problem solving was also introduced as a four-week add-on activity. At the six-month outcome point, 44% of participants no longer met clinical criteria for an ICD in the CBT group, compared to 29% in the waitlist control group. In addition, a secondary analysis of the same

trial on predictors of treatment response (Okai et al., 2015) found that pwPD scoring lower on burden of ICDs and neuropsychiatric scores, better social functioning, and lower dose of antiparkinsonian medication may benefit more from CBT.

The second study (Jiménez-Murcia et al., 2012) adopted a quasi-experimental design to compare pwPD experiencing pathological gambling to matched people with pathological gambling alone. Sixteen weekly sessions of CBT focused on psychoeducation and coping skills regarding the impulsivity difficulties and planning non-gambling pleasurable activities were offered to both groups. The results revealed no difference between groups on the South Oaks Gambling Screen measure following the intervention. However, higher dropout and relapse rates were observed among the PD participants compared to those without PD.

Psychosis

PwPD can experience different psychotic problems and these can fluctuate over the course of the condition but generally increase over time (Ffytche et al., 2017). In early PD, illusions, passage hallucinations (animal or person passing-by in the peripheral visual field), and presence hallucinations (a sense of someone nearby) may be relatively common, but do not tend to cause distress and indeed some may be similar to those experienced in the general population (Fénelon, Soulas, De Langavant, Trinkler, & Bachoud-Lévi, 2011; Pagonabarraga et al., 2016; Ravina et al., 2007; Wood, Hopkins, Moodley, & Chan, 2015) . As PD progresses, visual hallucinations, for example of people and animals can occur, initially with preserved insight, but evolving as cognition declines to partial loss (e.g., absent insight at the time of a hallucination but present in retrospect or when prompted) and full loss in the context of PDD (Ffytche et al., 2017). Loss of insight has been noted as a key determinant of increased caregiver burden (Renouf et al., 2018). Hallucination in other modalities, such as auditory (music or whispers), olfactory and tactile may also occur with increasing frequency (Goetz et

al., 2011). Delusions may also occur with some studies reporting fears of infidelity of partner or abandonment as key themes (Ravina et al., 2007) but others suggesting a broader content (Factor et al., 2014). However, psychosocial factors are also important in understanding the experience of these difficulties (Todd et al., 2010).

Different types of psychological treatment are likely to be required for different forms of psychosis; however, no study has been carried out so far to evaluate any psychological interventions at any stage. Very little is also known on how pwPD cope with these symptoms. For example, a survey of loosely defined psychological 'coping' strategies used in PD (Diederich et al., 2003) found that 69% of pwPDs used a strategy that relied on their own evaluation of the hallucination (e.g., self-reassurance or distraction), 62% used socially-interactive techniques (e.g., seeking re-assurance from others), and 33% used specific visual techniques (e.g., looking at, looking away or focussing on the object). More formal CBT for visual hallucinations has been suggested, derived from an approach developed for individuals diagnosed with schizophrenia (Collerton & Dudley, 2004). While this may have limited application with impaired insight and cognition, which would impair the ability to carry out the cognitive appraisal, content evaluation, or hallucination control components of the treatment, Diederich et al. (2003) noted that pwPDs with dementia were using cognitive self-reassurance or distraction strategies. Thus, CBT may still be useful even for PwPD with less insight and should be considered for future investigations.

Psychological approaches for more developed psychotic difficulties may also need to be considered more widely as extending to the caregiver/pwPD dyad or focussing on the caregiver themselves. For example, a form of brief psychosocial therapy developed initially for Alzheimer's disease (Ballard et al., 2009) but modified for PD (BPST-PD) has been used in the screening phase of a clinical trial for PwPD with psychosis to reduce subsequent placebo

responses (Cummings et al., 2014). Participants entered a 2-week lead-in period before trial enrolment with daily personalised therapeutic interactions between participant and caregiver. Although full details of the effects are not reported, of 314 participants screened for the study, 53 (17%) had improved sufficiently after two weeks of BPST-PD to no longer meet threshold criteria for study entry. Although other factors are likely to have been involved, BPST-PD may have contributed to this improvement as noted in a trial for Alzheimer's psychosis using similar lead-in methodology (Ballard et al., 2018).

Psychosocial difficulties

Six studies have explored the use of a psychological intervention to target psychosocial difficulties in pwPD, only one of which was an RCT (Flores Alves Dos Santos et al., 2017).

Santos et al. (2017) developed a group psychoeducation programme designed for pwPD undergoing subthalamic nucleus deep brain stimulation (STN-DBS) and it was evaluated against standard STN-DBS aftercare. The programme focused on three main domains (neurosurgical procedure and neurological outcome, social life impact including work, social and familial relationship, and couple relationship). The outcome was assessed using the Social Adjustment Scale (SAS; Weissman, 1975), which encompasses the domains of work, social life, family, couple, children and global social adjustment. The intervention involved providing information, managing expectations, and supporting coping, and was delivered through seven 2-hour small group sessions. The results showed no significant difference in social adjustment between the two groups at 1-year follow-up, although the finding became significant at 2-year follow-up.

Tiihonen et al. (2012) designed a quasi-experiment to evaluate a cognitive-behavioural patient education programme (EduPark) which included stress inoculation (resistance) training,

cognitive restructuring, social skills training, role play, and relaxation training. The univariate analysis of the results showed no significant improvements for psychosocial stress.

Macht et al. (2007) adopted an uncontrolled pretest-posttest design to explore a patient education programme based on information sessions, self-monitoring, health promotion, stress management, and management of depressive moods and anxiety across seven European countries (Spain, Finland, Italy, The Netherlands, United Kingdom, Estonia, Germany). The results showed significant improvements for psychosocial issues at post-intervention. A case series by the same author (Macht, Pasqualini, & Taba, 2007) reported improvement for pwPD experiencing psychosocial issues following the administration of CBT. However, no information on significance was included.

Lundervold et al. (2013) reported a case of a person with PD and social anxiety who showed improvements after four sessions of behavioural relaxation training (BRT), and maintained the benefits at follow-up. Finally, Heinrichs et al. (2001) reported on a person with PD who received 12 weeks of self-focused exposure therapy (SFET), a CBT programme including repeated in vivo exposure in session, video feedback, didactic training, and mirror exposure. The results showed significant short-term and long-term reduction social anxiety in both clinician ratings and self-report measures.

Quality of life and well-being

Quality of life (QoL) or, more specifically, health-related QoL (HRQoL) is a concept that refers to the impact of health status on quality of life, which is the subjective evaluation of one's own life. HRQoL is a multi-dimensional construct that encompasses several domains such as physical, mental, emotional and social functioning. In PD, HRQoL has been assessed using a variety of tools, and PD-specific tools have been developed, of which the Parkinson's Disease

Questionnaire (PDQ-39; Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995) and its shortened version, the PDQ-8 (Jenkinson et al., 1997) are the most common. Poorer HRQoL in PD has been associated with mental health difficulties, age of onset of motor symptoms, and other motor-related factors in PD (Leroi et al., 2011; Schrag, 2006; Schrag et al., 2000). Most studies have included pwPD with no significant cognitive impairment, but three were intended for people with mild cognitive impairment or dementia associated with PD.

CBT

Five studies have evaluated CBT interventions aimed at improving quality of life in pwPD, two of which were RCTs (Anousha Hadinia et al., 2016; Wuthrich & Rapee, 2019), one a quasi-experiment (Tiihonen et al., 2012), one an uncontrolled pretest-posttest design (Berardelli et al., 2015), and one a 'case series' (small number of participants but randomised to two groups; Veazey et al., 2009).

The experimental studies reported contrasting results. Hardinia et al. (2017) compared CBT to a health enhancement programme, an intervention based on a range of components offered at successive sessions, including music therapy, physical activity, dietary counselling, medical information, and a summing up session. The interventions were offered for two hours per week for nine weeks. The results showed significantly greater increases in QoL in the CBT group. On the other hand, Wuthrich and Rapee (2019) compared a telephone-delivered manualised CBT programme to controls placed on a wait list, and found no changes in the psychological subscale of the QoL measure (the only aspect of QoL measured). Finally, Tiihonen et al. (2012) evaluated a cognitive-behavioural patient education programme (EduPark) consisting of stress inoculation (resistance) training, cognitive restructuring, social skills training, role play, and relaxation training. The findings showed significantly less deterioration in HRQoL for the intervention group compared to the control group, when

considering HRQoL total score. However, a multivariate analysis on the HRQoL subscales as outcomes found no difference between groups.

A similar contrasting pattern was shown by the non-experimental studies, with Berardelli et al. (2015) reporting significant improvements in QoL post-intervention after group CBT, and Veazley et al. (2009) reporting no notable differences at all time points after mixed in-person and telephone-delivered individual CBT, but in both cases samples were very small meaning findings need replicating in larger samples.

Mindfulness

Five studies have explored the use of mindfulness-based interventions to address QoL in pwPD. These included three RCTs (Advocat et al., 2016; Pickut et al., 2015; Son & Choi, 2018) and two uncontrolled pretest-posttest designs (Birtwell et al., 2017; Dissanayaka et al., 2016).

Son and Choi (2018) developed a mindfulness meditation-based complex exercise program (MMBCEP), combining MBSR with a senior fitness test manual, and found significant improvements in quality of life compared to waitlist controls after eight weeks. Advocat et al. (2016) developed a group mindfulness-based lifestyle programme designed to introduce key lifestyle and mindfulness elements to participants, and compared it to controls placed on a waitlist. The results showed no significant differences in global quality of life between the two groups at post-intervention and six months. However, a secondary analysis of the same trial highlighted how, following the programme, many participants accepted disease progression more and reported improved social relationships and self-confidence (Vandenberg et al., 2018). No significant differences in quality of life were also observed by Pickut et al. (2015) after an 8-week mindfulness-based intervention compared to controls receiving usual care.

Considering the non-RCT studies Birtwell et al. (2017) evaluated the effects of an 8-week group MBSR course, and found no significant differences on measures of quality of life. Dissanayaka et al. (2016) reported significant improvements after an 8-week manualised group mindfulness intervention tailored for PD. However, the results were no longer significant at 6-month follow-up, likely due to a decrease in sample size caused by attrition. Thus generally findings are mixed for the impact of mindfulness on HRQoL.

Other approaches

Ghielen et al. (2017) carried out an RCT to evaluate a group body awareness training (BEWARE), based on ACT principles and consisting of psycho-education, training in ACT, imaginary exposure using FEEL (Feeling Experiences Enriches Living) exercises, diminishing avoidance behaviour, physical exercises, and homework assignments. The results showed a significant improvement in emotional well-being as measured with the PDQ-39.

Sproesser et al. (2010) developed an RCT to evaluate a 6-month group psychotherapy intervention based on psychodrama, and found significantly greater improvements in quality of life for the therapy group at post-intervention.

Guo et al. (2009) designed an RCT to evaluate an 8-week educational programme on "How to manage your routine Meal, Moving and Mood after suffering from IPD [idiopathic PD]", and found significantly greater improvements in quality of life for the intervention group.

Finally, Macht et al. (2007) adopted an uncontrolled pretest-posttest design to evaluate a pwPD education programme based on information sessions, self-monitoring, health promotion, stress management, management of depressive moods and anxiety across seven European countries (Spain, Finland, Italy, The Netherlands, United Kingdom, Estonia, Germany). The results showed no significant improvements in quality of life post-intervention.

Resilience, self-efficacy and coping

Resilience is a construct that has no single definition but has arisen from studies of childhood responses to adverse childhood experiences, and encompasses the notion of how well a person can 'bounce back' or recover from stressful circumstances. It is often used in a chronic illness context to indicate how well a person is able to manage after such a serious diagnosis. Self-efficacy includes the potential for an individual to influence their own circumstances, have increased confidence and cope with the challenges of daily life. Considering that PwD experience a progressive loss of function, ability and confidence as their condition progresses, a focus on improving resilience and self-efficacy is important. To date, there have been no studies of psychological therapies in PD with the specific aim of increasing resilience as an outcome although it has been measured recently as a secondary outcome in a trial of cognitive stimulation therapy for PwPD (Leroi et al., 2019).

While few studies considered these 'positive' concepts as outcomes (Barak & Achiron, 2009), there is an increasing need to consider how such outcomes can be best effected for people with long term conditions such as PD. A change – or extension - in focus to incorporate the notion of 'living well' with and successfully adapting to the condition, rather than 'cure' or 'reversal' of the symptoms, needs to take place

Sleep

Sleep disturbances may be seen in up to 96% of pwPD (Chaudhuri & Schapira, 2006) and have a significant negative impact on their own quality of life as well as the lives of their care partners (Happe & Berger, 2002). These disturbances include different types of insomnia, REM sleep behaviour disorder, excessive daytime sleepiness, restless leg syndrome, sleep attacks, sleep-disordered breathing, and nocturnal movements (Dhawan et al., 2006). Thus,

improvement in sleep quality of pwPD is an important component of intervention. Several studies have evaluated different types of pharmacological and non-pharmacological interventions for sleep problems associated with PD, although the focus is generally on insomnia. Pharmacological interventions may be problematic, particularly for pwPD, due to the risk of side effects including excessive daytime sleepiness, falls, and cognitive impairment. Thus, finding non-pharmacological interventions is important.

CBTi

CBT for sleep disorders, specifically insomnia (CBTi), is designed to target dysfunctional beliefs about sleep (Bootzin & Stevens, 2005) and there is growing evidence base of CBT for insomnia in non-PD populations (e.g., Brasure et al., 2016). CBT for sleep disturbance in PD was evaluated in five studies. Two RCTs incorporated CBT with other modalities (Leroi et al., 2010; Rios Romenets et al., 2013), one RCT used computerised CBTi (Patel et al., 2017), one was a small uncontrolled pretest-posttest pilot study using CBT alone in 22 pwPD (Yang & Petrini, 2012), and one was a small retrospective case series of five pwPD (Humbert et al., 2017). All five studies addressed insomnia as the primary sleep disorder of concern.

In the study by Leroi et al. (2010), 15 pwPD and sleep disturbances were randomised to either a simple sleep hygiene intervention or a 'multi-component' sleep therapy (MST), which was recommended by the American Association of Sleep Medicine as one of the most effective interventions for insomnia (Morgenthaler et al., 2006). The intervention, delivered every two weeks for six weeks, combined psychological and behavioural components, including group CBT (with a focus on sleep problems and medication use), sleep hygiene education, and progressive muscle relaxation. The main outcome measure, the Epworth Sleepiness Scale (Johns, 1991), designed to assess excessive daytime sleepiness, revealed significant improvements in both groups following the intervention.

Rios Romenets et al. (2013) randomised 18 pwPD into one of three intervention groups: six weeks of weekly group CBTi plus light therapy, doxepin 10mg, or sham light therapy. After six weeks, the insomnia severity score and subjective sleep quality improved significantly in the CBTi group compared to the sham light therapy group, which acted as a placebo, but no improvement in excessive daytime sleepiness was observed.

Patel et al. (2017) compared 6 weeks of computerised CBTi with standard sleep hygiene instructions. Those that completed the intervention had significantly improved insomnia scores compared to controls, but an intention to treat analysis showed no difference between the groups, perhaps because 43% of the intervention group did not complete it.

Yang and Petrini (2012) delivered four weeks of CBT to 25 pwPD with insomnia by telephone or face-to-face. The results showed significant improvements in total wake time, sleep efficiency, and overall sleep score at post-interventions and 3 months.

Finally, in the case series by Humbert et al. (2017), the data from five pwPD who had received CBTi and at least one follow-up visit was retrospectively examined using medical records and pre- and post-treatment sleep diaries. The results showed that sleep efficiency increased and number of awakenings per night decreased.

Stress

Four studies have so far evaluated the effectiveness of psychological interventions for stress reduction in pwPD. Two were RCTs which adopted group CBT (Hadinia et al., 2016; Troeung et al., 2014), while the other two were uncontrolled pretest-posttest designs which adopted mindfulness-based interventions (Birtwell et al., 2017; Dissanayaka et al., 2016).

Hadinia et al. (2016) compared nine weeks of group CBT against a health enhancement programme and found significantly greater reductions in stress for the CBT group at post-

intervention. Improvements in stress were also significantly correlated with improved emotional well-being and somatic motor function.

Troeung et al. (2014) compared a group CBT treatment consisting of psychoeducation, relaxation training, cognitive therapy, problem solving, and behavioural activation to controls placed on a waitlist. The results showed no significant improvements in stress at post-intervention. However, significant benefits were observed at the 1-month and 6-month follow-ups.

Birtwell et al. (2017) delivered an 8-week MBSR course, and found significant improvements in levels stress at both post-intervention and follow-up. The qualitative component of the study identified themes of 'mindfulness as challenging' and 'mindfulness as life-enhancing'. All participants reported they would recommend MBSR to other pwPD.

Finally, Dissanayaka et al. (2016) delivered eight weeks of a manualised group mindfulness intervention tailored for PD, and found a significant reduction in symptom distress at post-intervention. However, these benefits were not maintained at follow-up which may have been due to a sample size decrease caused by attrition.

Access to psychological services

Due to the emphasis on the motor difficulties, pwPD are usually seen within specialist neurology or geriatric medicine settings and are under the care of a neurologist or geriatrician specialising in movement disorders. Yet relatively few of these services have specialist psychological support available as part of the multidisciplinary team, despite the high level of mental health problems among pwPD (Neurological Alliance, 2017). More generally, there remains a paucity of specialist mental health service provision for pwPD compared to other neurological conditions and people can wait months or even years for support (APPG for

Parkinson's, 2018). NICE guidelines for Parkinson's disease (NICE, 2017) make no specific recommendations on how to support pwPD experiencing psychological difficulties but refer to guidelines on depression in adults with a chronic physical health problem without recognition of common psychological difficulties in PD such as anxiety and apathy. SIGN guidelines only focus on diagnosis and medication (SIGN, 2010a).

Previous position papers have stressed the need for specialist multidisciplinary PD clinics with input from mental health professionals integrated into the PD service, including those from neuropsychology, clinical psychology and psychiatry (e.g., APPG for Parkinson's, 2018; BPS Professional Practice Board, 2009). Healthcare Improvement Scotland's Clinical Standards for Neurological Health Services (2019) and the Welsh Neurological Conditions Delivery Plan (2017) similarly emphasise the importance of integrated care for neurological conditions generally. These multidisciplinary services are best placed to understand the chronic and fluctuating nature of PD and the complex interactions between neurobiological and psychological factors. There should be an emphasis on early assessment allowing for effective management psychological of difficulties (Shulman et al., 2002). Services also need to recognise that psychological difficulties change over the course of the progressive condition and services must try to avoid a model of care where clients are assessed then discharged (Bender & Wainwright, 2005), but rather provide for psychological problems from the point of diagnosis through to palliative care. Special consideration should also be given to those with young onset PD, who constitute around 5-10% of the PD population (Golbe, 1991). The needs of this subgroup differ in terms of occupational, financial and familial responsibilities. They also differ in terms of the clinical manifestation and prevalence of psychological difficulties, with the younger onset population more likely to develop impulse control disorders (Ceravolo et al., 2010) and anxiety (Nègre-Pagès et al., 2010).

A few models of good practice already exist and were highlighted through the recent APPG on Mental Health in Parkinson's disease (Specialist Assessment and Rehabilitation Centre in Derby and Parkinson's Advanced Symptoms Unit in Teesside, UK) and through the Parkinson's UK Excellence Network for Mental Health (National Hospital for Neurology and Neurosurgery, London, UK). However, it is widely recognised there are a number of constraints across the UK precluding optimal service provision, most notably in resources and shortages of key professionals. As such, most multidisciplinary teams (MDTs) rely upon input from existing mental health services, typically commissioned separately, which can impede the ability to deliver integrated physical and mental health care (APPG for Parkinson's, 2018).

Where mental health support is not embedded within multidisciplinary teams, provision of psychological therapies in England may be covered by Improving Access to Psychological Therapies Services (IAPT). NHS England's implementation of the five-year forward view for mental health recommends an expansion of IAPT services to provide support for people with long-term conditions. However, recent reviews suggest that IAPT at present may not be able to meet the needs of pwPD (APPG on Parkinson's disease, 2018). Nonetheless where therapies which can be provided through IAPT have been shown to be beneficial, e.g., cognitive behavioural therapy for depression, then there is a strong argument for making this more available. This could be part of a stepped care approach, with the option of access to more specialist clinical psychology support if needed. In Northern Ireland, mental health services are already not meeting their targets for waiting times and a shortage of specialist psychologists and neuropsychiatrists mean that even if people manage to be seen many people will see mental health professionals with no knowledge of Parkinson's (APPG for Parkinson's, 2018; Northern Ireland Department of Health, 2019). In Scotland general access to mental health services can also be challenging and the needs of older people with mental health needs may not be identified, with a lack of appropriate training and skills and

multidisciplinary working (APPG for Parkinson's, 2018; Scottish Care, 2019). In Wales the neurological conditions delivery plan (NHS Wales, 2017) acknowledges the shortage of psychology professionals but there are no firm actions as to how this will be addressed (APPG for Parkinson's, 2018). There is no specific Parkinson's pathway (APPG for Parkinson's, 2018). Thus, in all four nations services and professionals may lack the required knowledge and specialist supervision to adapt therapies taking into account idiosyncratic physical, cognitive and psychological aspects related to the condition. Previous recommendations were that non-neuropsychologists could be utilised to deliver psychological therapies but only under the supervision of clinical neuropsychologists or following additional specialist training (BPS Professional Practice Board, 2009). However, this is too restrictive and does not allow for the skills of other psychologists to offer input, is not feasible given the number of pwPD experiencing psychological difficulties and the corresponding number of psychologists available to offer support or the more recent increase in the potential of digital health interventions. The recent APPG for Parkinson's disease (2018) made a number of specific recommendations for how services could be improved in this regard.

Organisations and charities

Parkinson's UK

Parkinson's UK provides a range of support for people affected by Parkinson's across the UK. See https://www.parkinsons.org.uk/ for more details.

Cure Parkinson's Trust

This charity mainly funds research into a cure for Parkinson's. See https://www.cureparkinsons.org.uk/ for more details.

Spotlight YOPD

Spotlight YOPD aims to provide advice and support for people with younger onset Parkinson's disease (diagnosed under age of 50). See https://spotlightyopd.org/ for more details.

Lancaster University

MOTOR NEURONE DISEASE

Clinical description

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis (ALS), is a neurodegenerative condition characterised by the progressive degeneration of upper and lower motor neurons (Hardiman et al., 2017). It leads to muscle weakness and wasting, loss of movement, speech and swallowing impairments, and reduced respiratory functioning. The average survival after the onset of symptoms ranges between three and five years, and no cure is currently available (Chiò et al., 2009; Worms, 2001). The worldwide incidence of MND is about 2 in 100,000 people (Logroscino et al., 2010; Marin et al., 2017), and up to 10% of these are estimated to be due to a form of familial inheritance (Zarei et al., 2015).

The typical age of onset of sporadic MND ranges between 50 and 70, although it tends to occur earlier (40 to 50) in those with a hereditary variant (Andersen et al., 2012). The initial symptoms are usually subtle, and may include weakness in one of the limbs, difficulties with fine movements (e.g., buttoning up a shirt), foot drops while walking, wasting of the tongue, muscle twitches and cramps, and difficulties swallowing liquids (McDermott & Shaw, 2008).

The current clinical management of people with MND (pwMND) relies mainly on symptom management and palliative care, with the aim of improving or maintaining quality of life (Hobson & McDermott, 2016). With the progression of the disease, affected individuals can lose their ability to move, speak and eat and, in these cases, around the clock care becomes a necessity and measures such as non-invasive ventilation (NIV) and enteral feeding via a gastrostomy tube may be adopted to prolong survival (Andersen et al., 2012; Hardiman et al., 2017; Martin et al., 2016).

Diagnosis

No specific test for MND is currently available and the diagnosis is typically made by excluding any possible condition which may mimic similar clinical manifestations, such as multilevel diseases of the cervical spine or benign cramp fasciculation syndrome (McDermott & Shaw, 2008). While the identification of late-stage presentations is usually straightforward, the subtleness of the initial symptoms often makes early diagnosis more difficult, with a mean time between symptom onset and diagnosis confirmation of 10 to 18 months (Andersen et al., 2012). As it is often characterised by multiple medical examinations and uncertainty, the path to a diagnosis can also cause feelings of anxiety and depression in affected individuals and their significant others, which tend to increase up until the time when the diagnosis is eventually confirmed (Oliver, Borasio, & Walsh, 2011) and the 'bombshell' is dropped (Mistry & Simpson, 2013). This delay in diagnosis can translate into a significant challenge for pwMND's well-being, as evidence suggests that such a slow escalation to the point of diagnosis carries the risk of facilitating the adoption of coping strategies based on denial and avoidance (Maes et al., 1996; Stanton & Revenson, 2012; Zarotti, Coates, et al., 2019), ultimately leading to poorer quality of life (Hogg et al., 1994; Lee et al., 2001).

Type of onset

In the vast majority of cases, the onset of MND is characterised by weakness to one of the limbs, which then extends to the remaining ones, while other functions such as speech, swallowing, or breathing are usually affected at a later stage ('limb onset'; Chiò et al., 2009). However, around 30% of pwMND experience another type of onset, which is characterised by early swallowing and speech difficulties due to involvement of the bulbar regions of the brain ('bulbar onset'; Hardiman et al., 2017). This represents an important distinction, since people diagnosed with bulbar MND generally have a poorer prognosis (Chiò et al., 2009), as well as

higher levels of psychological distress (Goldstein et al., 2006; Hogg et al., 1994). Swallowing difficulties along with breathing difficulties and perhaps speech difficulties have been associated with greater depression (Hillemacher et al., 2004).

Cognitive impairments

While MND was traditionally thought to affect only motor neurons without altering cognitive skills (Phukan et al., 2007), more recent evidence has triggered renewed awareness on the neuropsychological impact of the disease. This has shown that between 40 and 50% of pwMND experience forms of cognitive impairment, in particular in the areas of executive functioning, language and verbal fluency (Abrahams, 2013; Niven et al., 2015). Moreover, about 10-15% of pwMND meet the full criteria for a diagnosis of frontotemporal dementia (Phukan et al., 2012; Ringholz et al., 2005) and some have proposed there might be a cognitive and behavioural continuum between the two conditions (Lillo et al., 2012; Murphy et al., 2007). As cognitive flexibility and flexible affective processing are predictors of trait resilience (Genet & Siemer, 2011), the MND related cognitive changes could affect individuals' ability to cope psychologically. Consequently, cognitive rigidity is likely to impact how well the person with MND responds to interventions.

Physical difficulties

The clinical progression of MND is characterised by the death of both upper and lower motor neurons, which leads to progressive muscular atrophy and eventually the complete loss of voluntary movements (Hardiman et al., 2017). Not surprisingly, these issues may carry a number of significant psychological repercussions for affected individuals, and may represent one of the major factors affecting the subjective experience of coping with the condition (Hecht et al., 2002),

The deterioration of the muscles required to produce vocal sounds, leading to the loss of ability to articulate speech (dysarthria), affects up to 80% of pwMND and this manifests early in people with bulbar onset (Tomik & Guiloff, 2010). The communication difficulties that develop as a consequence of dysarthria can often lead to several psychosocial problems (Hecht et al., 2002; Walshe et al., 2009), including negative emotions, changes to perceptions of identity, and feelings of self-consciousness (Dickson et al., 2008; Walshe & Miller, 2011).

Difficulty swallowing both solid food and liquids (dysphagia) represents another of the most common consequences of MND, affecting at least 75% of all pwMND (Heffernan et al., 2004; Leighton et al., 1994) and ultimately leading to the adoption of enteral feeding due to a significant risk of asphyxiation (Stavroulakis & McDermott, 2017). From a psychological standpoint, dysphagia has been linked to fear of choking (Borasio & Miller, 2001; Greenwood, 2013; Muscaritoli et al., 2012; Neudert et al., 2001), loss of pleasure deriving from eating (Johnson et al., 2012; Stavroulakis et al., 2014, 2016), as well as reduced feelings of control (Foley, Timonen, & Hardiman, 2014; King, Duke, & O'Connor, 2009; Oliver & Turner, 2010; Zarotti et al., 2019).

Psychological interventions

Anxiety and depression[2]

Anxiety and depression are frequently experienced by pwMND, with some studies estimating around 44% and 30% individuals, respectively, are affected (Kurt et al., 2007). In addition, not

[2] Since the retrieved studies addressing anxiety and depression in pwMND were the same, the two categories have been grouped together.

only are these difficulties distressing to the individual in their own right but they also are strong predictors, sometimes over and above the physical symptoms, of quality of life (Vignola et al., 2008). To date, four studies have carried out some form of intervention specifically to address both anxiety and depression in pwMND. Of these, only one (Pagnini et al., 2017) was an RCT, while the remaining studies either adopted an uncontrolled pretest - posttest design (Palmieri et al., 2012) or a quasi-experiment (Díaz et al., 2016; Kleinbub et al., 2015). In all studies, the outcome measure was the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

Pagnini et al. (2017) developed an RCT to evaluate an 8-week MND-specific meditation programme based on mindfulness-based stress reduction (MBSR) against treatment as usual. The results showed significant improvements for levels of anxiety and depression immediately post-intervention, as well as at 6- and 12-months follow-up. In addition, a secondary qualitative analysis of the same study adopting a grounded theory approach reported that both the participants and their caregivers believed the intervention had a positive impact on their psychological well-being, promoted by an increase in acceptance and a non-judgmental attitude (Marconi et al., 2016).

Díaz et al. (2016) delivered a short-term (i.e., 4 sessions) CBT programme combined with counselling techniques, and compared it to treatment as usual in a quasi-experiment. Assessments were carried out at baseline and post-intervention, with no follow-up. The results showed that the treatment group recorded a significant decrease in the proportion of participants with both moderate anxiety and severe anxiety (from 63.3 to 16.7%); there was also a significant decrease in the proportion of participants with moderate and severe depression (from 36.7 to 10.0%). The control group's anxiety and depression scores did not show any significant decrease.

Palmieri et al. (2012) adopted an uncontrolled pretest-posttest design to pilot a psychodynamic hypnosis-based intervention combined with domiciliary visits and self-hypnosis training. The results at post-intervention showed significant improvements in levels of both anxiety and depression. These findings were later corroborated when the intervention was trialled with a quasi-experimental study enrolling one-by-one matched controls with MND (Kleinbub et al., 2015), which reported significant improvements in both anxiety and depression immediately after the treatment and importantly, also at 3- and 6-month follow-ups.

Limitations

Psychological difficulties linked to anxiety and depression are considered a common consequence of being affected by MND. However, few studies report whether participants with MND showed clinically significant levels of both difficulties prior to the interventions, and current estimates on prevalence tend to vary considerably based on the adopted assessment tools (e.g., semi-structured interviews v. self-report questionnaires; Ferentinos et al., 2011). In addition, despite evidence of a differential impact of anxiety and depression based on onset type (Goldstein et al., 2006; Hillemacher et al., 2004; Hogg et al., 1994), none of the studies provided such distinction when reporting their results. As a consequence, caution is advised when drawing specific implications for clinical practice.

Quality of life

Since no treatment is available for MND, and considering the typically fast progression of the condition after the first onset of symptoms, the improvement and maintenance of quality of life represents the mainstay of current clinical management of pwMND (Hobson & McDermott, 2016). With regard to this, current evidence suggests that the psychological

difficulties experienced by pwMND may represent stronger predictors of poor quality of life than the physical impairments caused by the disease (Chiò et al., 2004; Sandstedt et al., 2016; Simmons, Bremer, Robbins, Walsh, & Fischer, 2000; van Groenestijn, Kruitwagen-van Reenen, Visser-Meily, van den Berg, & Schröder, 2016). However, to date, only five studies have explored interventions to address quality of life in pwMND – two RCTs (Pagnini et al., 2017; Van Groenestijn et al., 2015), one quasi-experiment (Kleinbub et al., 2015), and two[3] uncontrolled pretest-posttest studies (Aoun et al., 2015; Bentley et al., 2014; Palmieri et al., 2012). All the studies adopted MND-specific measures of quality of life, such as the Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ; Jenkinson, Fitzpatrick, Brennan, Bromberg, & Swash, 1999) or the ALS-Specific Quality of Life Revised (ALSSQoL-R; Felgoise et al., 2008).

Van Groenestijn et al. (2015) developed a CBT intervention based on a stress-coping model, consisting of six modules that could be specifically tailored to pwMND and their caregivers but had to stop the RCT prematurely due to issues with recruitment. However, the analysis of the data available up to the point of interruption of the study showed significantly lower deterioration in mental quality of life in the intervention group compared to controls receiving treatment as usual.

Pagnini et al. (2017) compared an 8-week MND-specific meditation programme based on MBSR with treatment as usual, and reported significant improvements in quality of life for the intervention group at post-intervention, as well as at six and 12 months after the intervention.

[3] Aoun et al. (2015) and Bentley et al. (2014) appear to report on the same data.

The benefits on quality of life were later corroborated by data from a qualitative exploration of the participants' experiences of the RCT (Marconi et al., 2016).

Palmieri et al. (2012) piloted a psychodynamic hypnosis-based intervention in combination with domiciliary support and training on self-hypnosis, and found significant improvements on the negative affect and spirituality components of quality of life. Kleinbub et al. (2015) later evaluated the same intervention with a quasi-experimental design. The results showed a small but significant improvement of total quality of life at post-intervention, which was retained at the 3-month follow-up. However, at the 6-month follow-up, the total score had decreased again towards pre-intervention levels.

Finally, an uncontrolled pretest-posttest feasibility study was conducted to evaluate dignity therapy (DT) with 27 pwMND and their caregivers in Australia (Aoun et al., 2015; Bentley et al., 2014). The median duration of the intervention was 36 days (range: 14 to 113), with an average of 4 visits per participant to complete it (range: three to seven). While DT was well received by the participants – including those who required augmentative and alternative communication (ACC) tools to interact with the therapists – no significant differences in quality of life were observed for either pwMND or their caregivers at the post-intervention assessment.

Other psychological difficulties

A review of qualitative research conducted as part of the recent NICE guidelines for MND (NICE, 2016) identified a number of other psychological concerns for pwMND. For example, PwMND understandably can struggle to come to terms with the diagnosis and therefore acceptance can be important, along with finding meaning in life and trying to retain a sense of control. The multiple losses experienced, such as losing a past self, identity and the future,

can give rise to hopelessness and frustration, as well as reduced well-being. Family and relationship concerns can also be prominent including worries about the impact on children, not seeing children grow up, change of roles within the family and loss of intimacy between couples.

Little research has been conducted on approaches which address these issues directly. However, one pretest-posttest study of dignity therapy specifically aimed to increase hope and spiritual well-being and reduce dignity-related distress for pwMND (Aoun et al., 2015). There were no changes in the quantitative measures of dignity-related distress, hopefulness or spiritual well-being as a group, perhaps due to low baseline rates of distress on these measures. However, as noted in the quality of life section, it was well-received by participants. In particular, 70% said it helped them feel closer to their loved ones, 67% said it helped them take care of unfinished business and 63% said it helped the person still feel like themselves and that they still had a role, thus the therapy may have benefits beyond those targeted in the measures.

Access to psychological services

NICE guidelines (2016) suggest that the psychological and emotional impact of MND and the psychological needs of pwMND should be discussed at multidisciplinary team assessments and other appointments and that the person should be referred to counselling or psychological services if specific support is needed. However, access to dedicated psychological support is patchy across the UK, with some specialist hospital services (including MND care centres) having access to psychology, but only a few having psychology or neuropsychology integrated within the team. The same is true for community neurological rehabilitation teams. Some community services have access to psychology, but this access is

not consistent across geographical regions. Specialist nurses and other members of the care team inevitably (and appropriately) provide some psychological support. However, their roles tend to be more focused on physical care needs, and they often do not have the time or the training to do more in-depth psychological work.

In some areas, hospices offer counselling support to pwMND, and sometimes also to family members of pwMND. However, this depends on the set-up of the hospice and it is not available everywhere. In addition, some counsellors might not have appropriate training or experience to manage when pwMND have significant cognitive or communication difficulties.

PwMND could potentially access generic mental health services (e.g., improving access to psychological therapies [IAPT] in England) but such services tend to be treat specific mental health problems, and practitioners would not always have experience working with people who have a physical health problem, let alone one that is life-limiting and can progress rapidly and where quick access to services is therefore needed. For pwMND experiencing depression, NICE guidelines for MND (2016) refer to the NICE guidelines for treatment of adults with depression and a chronic health problem (NICE, 2009b). However, difficulties in accessing mental health services and receiving appropriate care have been recognised generally for people with neurological conditions (Neurological Alliance, 2017) and pwMND have commented that healthcare providers generally seem to lack knowledge of MND (NICE, 2016). Therefore, there is a risk that such appointments could pathologise normal shock and grief responses to this disease and either be ineffective or actively unhelpful. In addition, due to the nature of the work and the short appointments, accessing support through mental health services would only be feasible for individuals who are in the early stages of the disease or who do not have significant cognitive or communication difficulties and both these, as well as psychological needs can change rapidly through the disease course (NICE, 2016).

The motor neurone disease third sector organisations, such as the Motor Neurone Disease Association (MNDA) and MND Scotland, are valuable resources, with volunteers, information leaflets, and members of staff who provide some support and can help signpost pwMND to local services. In addition, MND Scotland has a counselling service. However, these organisations do not provide more in-depth psychological support and instead rely on adequate local services being in place. Where support is not available through the NHS or other public sector or charitable organisations, the only other option would be for people to access private therapy. Obviously, this has cost implications and would exclude some people from accessing the help they need.

Organisations and charities

MND Association

The MND Association funds research and provides a range of practical and emotional support for people affected by motor neurone disease in England, Wales and Northern Ireland. See https://www.mndassociation.org/about-mnd/ for more details.

MND Scotland

MND Scotland provides support and advice to people affected by MND living in Scotland. See https://www.mndscotland.org.uk/ for more information.

Lancaster University

MULTIPLE SCLEROSIS

Clinical description

Multiple sclerosis (MS) is a chronic inflammatory autoimmune neurological[4] condition that affects the central nervous system (CNS) and causes damage to myelinated axons. The course of MS is unpredictable, a function of both the location of lesions and auto-inflammatory processes (Goldenberg, 2012). At present, MS is treatable but not curable, and continues to represent one of the most common causes of physical disability in young adults (Brownlee et al., 2017). Prevalence estimates vary within the UK and range from 96 per 100,000 in Guernsey to more than 200,000 in Scotland and Northern Ireland, and prevalence (and incidence) seem to be increasing (Kingwell et al., 2013). People with MS (pwMS) often report a lower quality of life (McCabe & McKern, 2002) and increased psychological distress, even when compared to other neurological conditions (Brands et al., 2018; Ryan et al., 2007).

It has long been hypothesised that psychological factors can impact physical health for pwMS. MS was first diagnosed by Jean-Martin Charcot in 1868, and he later suggested that psychosocial stressors such as changes in social circumstance may trigger or exacerbate MS symptoms (Charcot, 1877). Indeed, in recent times psychological stress has been found to be associated with exacerbation of MS symptoms (Mohr et al., 2004), and interpersonal stress has been positively associated with brain lesions on magnetic resonance imaging (MRI; Mohr et al., 2000; Mohr et al., 2012). This suggests a complex interplay between psychological factors and physiological factors for pwMS.

[4] Whether MS should be classified as an immune or neurodegenerative disease is a matter of debate, although it has been argued that the primary cause of neurological impairment is neurodegeneration (Trapp & Nave, 2008).

Since the 1940s, depression has been widely studied for pwMS (Canter, 1951; Philippopoulos et al., 1958; Siegert & Abernethy, 2005), whereas anxiety has comparatively been less well researched (Marrie, Reingold, et al., 2015). However, depression and anxiety are known to be more common difficulties for pwMS compared to the general population (Anthony Feinstein, Magalhaes, Richard, Audet, & Moore, 2014; Hoang, Laursen, Stenager, & Stenager, 2016; Janssens et al., 2003; Patten, Beck, Williams, Barbui, & Metz, 2003), and they appear frequently together in pwMS (Marrie et al., 2013; Marrie, Reingold, et al., 2015; Wood et al., 2013).

Diagnosis

Diagnosing MS can be challenging due to the varied locations of lesions in the CNS, which can be associated with a wide range of symptoms and presentations (Brownlee et al., 2017). This can sometimes lead to a delay in diagnosis, or even misdiagnosis (Edwards et al., 2008). Perhaps exacerbated by the uncertainty around diagnosis, feelings of anxiety and stress during this period are commonly reported and can even exceed levels of anxiety post-diagnosis (Giordano et al., 2011; Isaksson & Ahlström, 2006; Murray, 1995; Mushlin et al., 1994).

MS most commonly presents between 20 and 40 years of age (Rejdak et al., 2010). The diagnosis therefore often coincides with important life events, such as trying to establish a career or start a family. Its effects can be wide-reaching, impacting employment and financial stability, family relationships, life-goals and well-being (Dennison, Moss-Morris, & Chalder, 2009; Malcomson, Dunwoody, & Lowe-Strong, 2007; Simmons, 2010). In addition to the unpredictability and impact of symptoms, pwMS also have to negotiate challenges associated with choosing medication and managing medication side-effects in addition to anxiety regarding potential future physical disability (Dennison et al., 2009).

Impact on employment

Due to the typically young age of onset, employment is an often-cited area of concern for pwMS, impacting financial considerations, feelings of self-worth, and social contact (Simmons, Tribe, & McDonald, 2010). In the general population, unemployment has been linked to reduced psychological well-being (Karsten & Moser, 2009; McKee-Ryan et al., 2005) and a similar relationship has been shown for pwMS (Miller & Dishon, 2006). High unemployment rates amongst pwMS are a common finding (Cadden & Arnett, 2015), even compared to people with other chronic illnesses (Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; Simmons et al., 2010). Unemployment rates have been reported to be as high as 80% (Kornblith et al., 1986), although a more recent review estimated mean unemployment rates at 59% (Schiavolin et al., 2013). People are more likely to become unemployed as the illness progresses (Busche et al., 2003), although high levels of work absence are reported in general, particularly around the time of diagnosis (Doesburg et al., 2019). Both fatigue and cognitive symptoms are frequently linked to unemployment for pwMS (Cadden & Arnett, 2015; Julian et al., 2008; Schiavolin et al., 2013; Simmons et al., 2010) and the lack of adjustments offered by many organisations to retain individuals in work is notable. Indeed almost 30% of pwMS report employment discrimination (Roessler et al., 2011).

Unpredictability of MS

MS follows a variable course due to the position of lesions in the CNS (Brownlee et al., 2017). Therefore, it can be difficult to predict clinical course and impact of symptoms (Langgartner et al., 2005). This unpredictability, as well as the uncertainty around future functional levels, may contribute to the high co-occurrence between anxiety and depression that are reported in the MS population (Boeschoten et al., 2017). As MS progresses, new symptoms can emerge that may have a significant impact on daily life and cause psychological distress (Irvine et al.,

2009). People who are more physically impacted by MS report higher rates of depression compared to those with fewer physical symptoms (Chwastiak et al., 2002). However, psychological adjustment can vary over the course of the illness and in one study, people who had a shorter duration of MS were more likely to experience significant depressive symptoms than those with longer duration (Chwastiak et al., 2002). The unique and wide-ranging uncertainties associated with MS (Barker-Collo et al., 2006) can impact on how well a person adjusts to their diagnosis (Dennison et al., 2009; Irvine et al., 2009), with people who perceive greater uncertainty showing poorer adjustment to their illness (Sullivan, Wilken, & Rabin, 2004).

MS subtypes

While MS is often conceptualised as a unitary condition, there are different types of MS that vary in clinical course (Goldenberg, 2012). Relapsing-remitting MS (RRMS) is the most common presentation, affecting up to 85-90% of people diagnosed with MS (Polman et al., 2011) and is characterised by periods of remission alternated with unpredictable relapses, which cause the onset of acute symptoms (Loma & Heyman, 2011; Siddiqui et al., 2018; Weiner, 2008). Recovery from relapses is variable (Ransohoff & Lucchinetti, 2015; Weiner, 2008) and can often be accompanied by residual symptoms (Lublin et al., 2003). For people living with RRMS, the illness is often stable for long periods of time, with relapses occurring every 2 years on average (Ransohoff & Lucchinetti, 2015). During the acute phase of relapses depression rates tend to increase (Moore et al., 2012), and high levels of emotional distress have been reported (Reynard et al., 2014).

As RRMS develops over time it can transition into secondary progressive MS (SPMS). SPMS is characterised by a gradual increase in symptoms over time (Ransohoff & Lucchinetti, 2015) affecting both physical and cognitive functions (Goldenberg, 2012; Planche et al., 2016). SPMS

has been known to develop between 5 to 35 years after initial onset (Ransohoff & Lucchinetti, 2015). Current estimates suggest over 80% of people with RRMS will transition to SPMS (Fisniku et al., 2008) and 75% will transition within 30 years of diagnosis (Tremlett et al., 2008). The period when a person is transitioning from RRMS and SPMS can be particularly psychologically challenging (Bogosian, Morgan, & Moss-Morris, 2019), and SPMS has been linked with higher rates of depression compared to people living with RRMS (Jones et al., 2012; Mohr et al., 2000).

Primary progressive MS (PPMS) is another variant which follows a progressive course from the time of diagnosis with no relapsing-remitting phase (Brownlee et al., 2017). Following onset, symptoms emerge gradually but steadily, and often with limited recovery. Up to a quarter of people living with PPMS need assistance to walk 7 years after diagnosis (Miller & Leary, 2017). PPMS is less common than RRMS, affecting approximately 10-15% of people diagnosed with MS (Lublin et al., 2014) but it has been shown that both depression and anxiety are common in PPMS (Hamel et al., 2015).

Lastly, progressive-relapsing multiple sclerosis (PRMS), which is characterised by the occurrence of relapses within a progressive course of MS, represents the least common subtype of MS and affects approximately 5% of people diagnosed with MS (Goldenberg, 2012).

Finally, prior to receiving a formal diagnosis, a person may be diagnosed with Clinically Isolated Syndrome (CIS) or Radiologically Isolated Syndrome (RIS). In CIS a person may experience symptoms indicative of demyelination, but there is insufficient evidence to diagnose MS formally (Lublin et al., 2014). Alternatively, in RIS there may be evidence of demyelination on an incidental MRI scan although the individual has not presented with clinical symptoms (Lublin et al., 2014). Although MS has not been formally diagnosed in either

CIS or RIS, levels of depression and anxiety are high for both (Bianchi et al., 2014; Labiano-Fontcuberta et al., 2015).

Traditionally, the majority of MS-related research has examined RRMS, leaving the progressive variants relatively understudied (Anthony Feinstein et al., 2015). As current medical treatments for SPMS and PPMS are limited, the facilitation of symptom management and the development of coping strategies tend to be prioritised (Beiske et al., 2007; Lublin et al., 2014; Sgoifo et al., 2017). This can represent a particular psychological challenge for people with SPMS, who have previously relied on medications to manage their symptoms in the remittent-relapsing phase and may experience a lack healthcare support once medication is stopped (Bogosian et al., 2019).

Psychological interventions

Adjustment

Despite some level of conceptual confusion around the concept of adjustment (see Moss-Morris, 2013) it is usually understood as the ways (or the overall outcome from those strategies) in which a person responds to living with chronic illness, and can be positive (adaptive) or negative (maladaptive; Dekker & de Groot, 2018). Given the personal, social and financial impact of the condition and the fact MS is often changeable and unpredictable (De Ridder et al., 2000), adjustment can be challenging (Dennison et al., 2009). Some evidence suggests that people with progressive forms of MS require more frequent adaptations (i.e., necessary changes in response caused by significant illness or life events) compared to people with RRMS (Bogosian, Hughes, Norton, Silber, & Moss-Morris, 2016; Gaudino, Chiaravalloti, DeLuca, & Diamond, 2001). Both environmental and contextual changes are seen as important determinants for positive adjustment (Bogosian et al., 2016) and adjustment for pwMS can

be usefully construed as a lifelong process (Tabuteau-Harrison et al., 2016). According to a review by Dennison and colleagues (2009), a higher level of perceived stress, emotion-focused coping, and illness uncertainty or uncontrollability are strongly and consistently related to a poorer psychological adjustment to MS.

CBT

Of the four controlled studies which measured adjustment in a more global sense (das Nair, Kontou, Smale, Barker, & Lincoln, 2016; Forman & Lincoln, 2010; Mohr, Hart, & Vella, 2007; Moss-Morris et al., 2013), two used individual interventions, one over the telephone (Mohr et al., 2007) and one face to face (Moss-Morris et al., 2013). While both reported improvements immediately after the intervention, only one (Moss-Morris et al., 2011) found improvements at one-year follow-up.

The two studies which used group interventions (das Nair et al., 2016; Forman & Lincoln, 2010) seemed to use some of the same participants and adopted exactly the same measures. Das Nair et al. (2016) compared individual and group interventions, with no significant differences between the groups after the intervention, although a trend was reported towards better outcomes for the individual approach, which was also better attended. In the Forman and Lincoln study (2010) the intervention group was less depressed at follow-up than the wait-list control group, but no other significant differences emerged on the other measures included as part of the adjustment concept.

Mindfulness

The one study (Hocaloski et al., 2016) which examined sexual adjustment used a 'mindfulness psychoeducational' group intervention with an uncontrolled sample of six women. No

differences were found at any time point for any of the overall sexual functioning measures, although some subscale improvements (desire and arousal) were reported.

Limitations

Unlike some of the other intervention targets, such as depression, which tend to be characterised by a relatively consistent conceptualisation and measured with single measures, adjustment in pwMS is often operationalised and measured in different ways. Of the five studies where adjustment featured in the title of the article, four (das Nair et al., 2016; Forman & Lincoln, 2010; Mohr et al., 2007; Moss-Morris et al., 2013) addressed adjustment using multiple measures which – in line with models of adjustment which emphasise both indicators of positive and negative well-being – included measures of depression, self-efficacy, illness impact, and quality of life. Theoretical critiques of the concept of adjustment have drawn attention to its inconsistent conceptualisation and therefore the inherent problems in its measurement (e.g., Moss-Morris, 2013). Although these individual outcomes could be extracted and included in other sections, this section on adjustment keeps the conceptualisation of the authors. The only paper which offered a different view on adjustment was Hocaloski et al.'s study (2016), which was specifically focused on sexual adjustment. Thus, such diversity of methods and approaches should be carefully taken into consideration when interpreting the results reported above.

Anxiety

Within the MS population, depression and anxiety often co-occur in individuals (Marrie, Fisk, et al., 2015). PwMS have been found to have high levels of anxiety (Wood et al., 2013), with estimates ranging from between 15.8% and 57% of individuals affected (Feinstein, O'Connor, Gray, & Feinstein, 1999; Garfield & Lincoln, 2012) and a recent meta-analysis suggesting a

pooled prevalence of 34.2% for clinically significant symptoms (Boeschoten et al., 2017). It has been suggested that anxiety may be severe and prolonged due to the uncertainty and unpredictability of how the illness will change, and impact of current and future symptoms on daily life (Butler et al., 2019; Janssens et al., 2004). There has also been some evidence that anxiety is more prevalent in people with RRMS compared with other MS subtypes (Pham et al., 2018).Anxiety interventions have been less well studied than those for depression. .

CBT

Individual interventions

No RCTs were found investigating individual CBT-based interventions for anxiety in pwMS. However, preliminary evidence is available from a number of non-experimental studies. One study (Askey-Jones et al., 2013) explored individual face-to-face CBT with 22 individuals with MS, adopting an uncontrolled pretest-posttest design. The results showed a statistically significant decrease in anxiety post-intervention, including for those with severe anxiety.

Two investigations adopted a case study design. Cox et al. (2004) found evidence for the efficacy of a 6-session CBT in treating self-injection anxiety and phobia, while Léger et al. (1998) reported an individual whose generalised anxiety disorder significantly improved after 11 sessions. Carrigan et al (2018) presented a case series on focused on a CBT intervention for health anxiety in people with RRMS. Over six face-to-face sessions, three of the participants demonstrated notable reductions in health anxiety while one participant showed a non-significant increase in anxiety. Improvement remained consistent at 5-month follow-up, while the latter participant dropped out.

Group Interventions

Three RCTs have examined the effects of group-based CBT for anxiety in pwMS. Pahlavanzadeh et al. (2017) adopted an 8-week intervention designed specifically for women with MS, and found that CBT had significantly reduced levels of stress and anxiety, both at post-treatment and 1-month follow-up. Similarly, Sayyah et al. (2016) evaluated an 11-session group-based CBT intervention for women with MS to help manage obsessive-compulsive disorder (OCD) symptoms. Significant improvements in OCD symptoms at post-intervention were observed for the treatment group compared to wait list controls. However, no follow-up assessments were performed. Finally, Robati and Shareh (2018) employed a 10-session weekly group format compared to waiting list, and found significant improvements in levels of anxiety at post-treatment. Again, no follow-up data were obtained.

ACT

Individual interventions

One RCT by Proctor et al. (2018) piloted a telephone-supported ACT bibliotherapy intervention compared to usual treatment people with MS, and found a significant effect of ACT on anxiety at post-intervention. However, as the authors reported high levels of attrition in the intervention group (33% drop-out), further adaptation is warranted to ensure the feasibility of such intervention on a wider scale.

Group interventions

Nordin and Rorsman (2012) compared a 4-session group-based ACT intervention to relaxation training with a small sample of pwMS. However, the results of the between group comparisons did not show any significant difference between ACT and relaxation training on anxiety levels either at post-intervention or 3-month follow-up.

Mindfulness

Five studies have investigated the effect of group mindfulness interventions on anxiety in people with MS. Cavalera et al. (2018) carried out an RCT adopting an 8-week online meditation programme for pwMS. In comparison to an active psychoeducational control group, anxiety was found to be significantly lower in the treatment group post-intervention, although this difference was no longer significant at the 6-month follow-up.

Kolahkaj and Zargar (2015) studied an 8-week mindfulness-based stress reduction (MBSR) course in women with MS. The findings showed a significant reduction of levels of anxiety in the treatment group at post-intervention as well as at 2-month follow-up. Similar results were observed in the exploratory RCT carried out by Simpson et al. (2017), which also used an 8-session MBSR, and found highly significant improvements in anxiety at post-intervention and 3-month follow up.

A quasi-experiment of a mindfulness course inspired by MBSR found reductions in trait but not state anxiety in the intervention group compared to controls (Crescentini et al., 2018), but no follow up data were collected. Finally, Gilbertson and Klatt (2017) adopted an uncontrolled pretest-posttest design to assess the feasibility of an 8-week Mindfulness in Motion programme (which incorporates yoga and relaxing music as well as meditation). While the results showed statistically significant improvements for anxiety at the 1-week post-treatment assessment, again no further follow up data were collected.

Other approaches

A number of studies have adopted alternative approaches to interventions targeting anxiety in pwMS. One RCT (Carletto et al., 2016) compared 10 sessions of EMDR to relaxation therapy for the treatment of PTSD in pwMS. Although both approaches reduced levels of PTSD

symptoms and severity significantly, EMDR was found to be more effective than relaxation training. These effects were maintained after 6 months. Blair et al. (2017) adopted a quasi-experimental design to assess the feasibility of a group DBT intervention with pwMS and comorbid anxiety or depression compared to usual treatment. The intervention consisted of 16 sessions of DBT twice a week, and showed low levels of attrition as well as high levels of acceptability by pwMS. The results showed a significant effect post-intervention on clinician-rated measures of anxiety compared to treatment as usual. However, the effect was only marginal on self-rated measures of anxiety.

McGuire et al (2015) also carried out a quasi-experiment to assess the effectiveness of a 10-week psychoeducational wellness group programme for pwMS. Anxiety was shown to improve significantly at post-intervention. Another quasi experiment (Tesar et al., 2003) adopted a combination of psychological therapies integrated into a single treatment programme, which included CBT strategies, elements of stress-coping training, and specialised exercises to influence perceptions of body image and body experience. Although changes were seen on other outcomes, no differences in anxiety were found between the intervention and control groups post-intervention and no changes in anxiety were seen within the intervention group.

Jongen et al (2016) adopted a 3-day self-efficacy programme, 'Can Do', in an exploratory and uncontrolled study involving pwMS and their partners. Significant improvements in anxiety levels were observed at post-intervention for people with RRMS, but not for people with PPMS.

Crawford and McIvor (1985) evaluated a 50-session intensive and insight-oriented psychotherapy group for 32 PwMS. Although the results showed some improvements in other domains, there was no significant difference from baseline to post-intervention on anxiety.

Two pretest posttest group interventions examined positive psychology techniques, one combined with CBT (Anderson, Turner, & Clyne, 2017) and one positive psychology alone (Leclaire et al., 2018) and both found that anxiety was not significantly reduced post-intervention.

Finally, Slatter (2016) reported a case study of an individual treated with hypnosis as an adjunct to CBT over 6 sessions. The results suggest that the use of hypnosis may enhance the efficacy of CBT by increasing feelings of relaxation decreasing levels of anxiety.

Limitations

Anxiety can be a complex concept to evaluate, as some studies target specific types such as health anxiety or needle phobia, while others typically operationalise it as a broader construct. This represents a considerable limit to the generalisability of results. Moreover, many investigations do not require individuals to have clinical levels of anxiety at baseline, thus making significant changes more difficult to detect and potentially less meaningful from a clinical standpoint.

Apathy

Apathy can be defined as a lack of motivation, impacting goal directed behaviour and thought and presenting as flat affect (Marin, Biedrzycki, & Firinciogullari, 1991). It has been shown to be common in pwMS (Rosti-Otajärvi & Hämäläinen, 2013), and men seem to be more impacted than women (Novo et al., 2016). A meta-analysis has estimated the prevalence of apathy at 22% (Rosti-Otajärvi & Hämäläinen, 2013). Despite this, apathy has been comparatively understudied compared to other difficulties (Raimo et al., 2014). Despite being a common difficulty in pwMS (Novo et al., 2016; Raimo et al., 2019), no intervention studies have been carried out so far to target apathy as a primary outcome in pwMS. However, a small

number of interventions have addressed related constructs, such as activation – as defined by individuals' levels of knowledge, confidence, and skills for managing their health.

Ehde et al (2015) carried out an RCT to evaluate a telephone-assisted self-management intervention compared to a solely educational programme, and included activation and negative affect as secondary outcome measures. The results showed that the participants in the self-management group had significantly higher motivation at post-intervention, but not at 12-month follow-up. Moreover, the authors did not note any statistically significant change on negative affect in the intervention group.

Langenmayr and Schottes (2000) employed a 15-month psychotherapy intervention in a quasi-experiment with people with MS. The results showed that, compared to the unspecified control group, the participants who engaged in therapy reported more changes in individual initiative, with results maintained at two years' post-intervention.

Body image

Body image is conceptualised as part of the self-concept and incorporates experiences and representation of the body along with appraisals of and attitude towards the body and its function. While it is unclear whether levels of dissatisfaction with body image generally differ from the general population (Stevens et al., 2019), pwMS can experience difficulties with body image, even when physical symptoms are mild (Pfaffenberger et al., 2011) and can experience a changed relationship with their body (Mozo-Dutton et al., 2012).

Only one study has looked a body image in MS. Tesar et al. (2003) adopted an integrated therapy included CBT strategies, elements of stress-coping training, and specialised exercises to influence perceptions of body image and body experience in a quasi-experiment. On the outcome measurement looking at body image, the vitality and body dynamics factor differed

between the groups at immediate follow up but not at the 2-month follow up. No changes were seen on the other factor "disapproval towards the body".

Coping and resilience

Coping can be conceptualised as the cognitive and behavioural strategies used to manage psychological (or other) difficulties (Folkman et al., 1986). Resilience refers to the process by which a person adjusts when faced with adversity (Black & Dorstyn, 2015) and the ability to adapt and endure when faced with stressors (Bonanno, 2004). Different coping strategies can be adopted in the face of psychological stressors (Brands et al., 2018), but the effectiveness of such coping strategies varies. Although perhaps an overly simplistic distinction, emotion-focussed and avoidance coping strategies have been linked to poorer adjustment, whereas problem-focussed coping style has been linked to better adjustment (Kar, Whitehead, & Smith, 2019; McCabe, 2006; McCabe, McKern, & McDonald, 2004; Pakenham, Stewart, & Rogers, 1997). For pwMS, active coping strategies have been shown to be more effective than avoidant coping strategies (Bogosian et al., 2016). However, pwMS have been shown to use more emotion-focussed coping strategies, including wishful thinking, avoidance and denial, and less problem-focussed coping and this has in turn been associated with reduced quality of life and poorer adjustment (Arnett, Barwick, & Beeney, 2008; Brands et al., 2018; Haase, Lienemann, & Faustmann, 2007; Kar et al., 2019; Lode et al., 2010; McCabe et al., 2004). Moreover, pwMS have been shown to use task-oriented coping most often, alongside avoidance and emotion-oriented coping (Brands et al., 2018).

Resilience is an area that has been understudied for pwMS, but there has been some evidence that the chronic and changeable nature of MS can impact on resilience (Silverman et al., 2017). Coping and resilience therefore reflect important areas for intervention and support.

Six studies have focused on interventions aimed at enhancing coping or resilience in pwMS. Of these, two were RCTs (Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987; Rigby, Thornton, & Young, 2008), two a quasi-experiment (Feicke et al., 2014; Tesar et al., 2003), and two adopted an uncontrolled pretest-posttest design (Pakenham et al., 2018; Sinclair & Scroggie, 2005).

Foley et al. (1987) compared the effect of stress inoculation training (i.e., CBT + deep-muscle relaxation) on coping against standard treatment. The results showed that, at post-intervention, the CBT group was significantly more likely to use problem-focused coping strategies than controls, along with significant differences in depression and anxiety.

Rigby et al. (2008) used group psychotherapy based on CBT principles coupled with educational material produced by the MS society, and compared it to the combination of education material and non-structured social discussions, and education material alone. Follow ups were at five point up to a year. While the ANOVAs suggested no changes at each time point in any group, analysis based on area under the curve (which take into account changes across the 12 months) suggested the two groups had greater increase in resiliency than the education material alone.

Tesar et al. (2003) adopted a combination of psychological therapies integrated into a single treatment programme, which included CBT strategies, elements of stress-coping training, and specialised exercises to influence perceptions of body image and body experience. Coping was assessed with the Freiburg disease coping questionnaire (FKV-LIS SE; Muthny, 1989). Results showed a significant reduction in the therapy group in coping with the disease in a depressive style, with a clear reduction in the anxious/depressive approach and associated feelings of helplessness and resignation towards the illness. Feicke et al (2014) compared a 5-session group self-management programme for pwMS with the provision of self-management

brochures covering the same content and found the self-mangement group's coping improved.

Another uncontrolled study of a group-based programme with CBT components called "beyond MS" which involved five sessions found reductions in maladaptive coping and increases in adaptive coping (Sinclair & Scroggie, 2005).

Pakenham et al. (2018) adopted the REsilience for Adults EverydaY (READY), a 13-week group training programme based on ACT principles, with a group of 37 people with MS. The findings showed significant improvements for resilience (along with other factors). The programme feasibility was supported by positive participant feedback, high rates of recruitment, attendance, retention, homework engagement, and good intervention fidelity.

Depression

Depression is perhaps the most commonly recognised and highly reported psychological difficulty for pwMS (Solaro et al., 2018). Estimates of pwMS affected by low mood vary but lifetime estimates have been reported to be as high as almost 60% (Pandya et al., 2005), and four times higher than rates reported in the general population (Schürmann & Margraf, 2018; Weinberger et al., 2018). Some evidence also suggests that MS subtype influences development of depression, with people with progressive MS more likely affected (Solaro et al., 2018) as well as those with more physical and cognitive difficulties (Chwastiak et al., 2002). This demonstrates the importance of early identification and effective treatment of depression for pwMS.

CBT

Individual interventions

Six studies have looked at individualized face-to-face CBT for pwMS. Two RCTs using the same sample (Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001; Mohr et al., 2004) identified a significant effect of manualised CBT for pwMS and depression over the course of 16 sessions, which was maintained at 6-month follow-up. Four additional studies have looked at face-to-face CBT for depression including a pilot RCT (Kiropoulos et al., 2016), two pre-post studies (Askey-Jones et al., 2013; Chruzander et al., 2016) and a single-case study (Wong & Laidlaw, 2012). Two of these studies found that the interventions were associated with a significant reduction in depression (Askey-Jones et al., 2013; Chruzander et al., 2016; Kiropoulos et al., 2016), but only one of these studies reported follow-up data, which showed significant continued improvement in depression at three months post-treatment (Kiropoulos et al., 2016). Despite reporting qualitative evidence of reductions in depression, two studies did not provide statistical analyses due to study design (Chruzander et al., 2016; Wong & Laidlaw, 2012).

Across studies, the number of sessions varied from eight to 20, usually occurring weekly and lasting 50 minutes, and often tailored to each individual. Only one study devised a therapy manual for treatment (Kiropoulos et al., 2016). There was some limited consideration of adapting treatment to address MS specific psychological challenges.

Overall the evidence seems to support individual face-to-face CBT as clinically effective for treatment of depression for pwMS. However, the majority of studies did not break down participants by MS subtype, so it is unclear whether CBT is equally effective for all subtypes of MS. Where subtypes were specified, the results showed that the majority of participants were diagnosed with RRMS. In addition, only one study reported considerations of adaptations for

providing therapy to participants with increased physical difficulties that may have impacted attendance (Askey-Jones et al., 2013). This suggested that home visits can be helpful for patients who may have difficulties travelling to weekly appointments. Nevertheless, the length of treatment reported in these studies was 11-20 sessions, which may be longer than some short-term CBT services are able to offer.

Ten studies have looked at computerised or telephone-administered CBT for pwMS and depression, five of which were RCTs (Beckner, Howard, Vella, & Mohr, 2010; Ehde et al., 2015; Fischer et al., 2015; Mohr et al., 2005; Mohr et al., 2000).

Four studies have shown significant post-treatment reductions in depression scores compared to waitlist and alternative therapy control groups (Mohr et al., 2000; Mohr et al., 2005; Fischer et al., 2015; Beckner et al., 2010). Interventions varied between 8-16 sessions of 50 minutes, and two studies reported evidence of treatment gains that were maintained after 6 and 12 months (Mohr et al., 2005; Fischer et al., 2015). Secondary analysis of Mohr et al. (2005) suggested depression outcomes for those who also had a diagnosis of an anxiety disorder were similar to those without, although the outcomes at follow up were mixed, depending on the type of anxiety experienced (Burns, Siddique, Fokuo, & Mohr, 2010). Additionally, one study showed telephone-based CBT was more effective than supportive-emotion focussed therapy, and that it was successful in reducing the frequency of depression diagnoses (Mohr et al., 2005). A further RCT examined telephone-based CBT, over eight weekly sessions of 45-60 minutes, but reported no significant effect compared to a control group receiving psychoeducation (Ehde et al., 2015). Both groups showed a statistically significant reduction in depression after treatment which was sustained at 6 and 12 months and depression severity was not a significant moderator of treatment outcomes (Ehde et al., 2018).

The remaining five non-RCT studies adopted a range of designs, including a case series of two participants (Wain et al., 2011), a qualitative analysis (Hind et al., 2010), a pilot RCT (Cooper et al., 2011), a pilot feasibility study (Boeschoten et al., 2012) and a secondary analysis of a previous RCT comparing MS to other neurological conditions (Tietjen, Wilson, Amiri, & Dietz, 2018). Due to the range of methods employed, four studies did not report group statistical outcomes (Cooper et al., 2011; Hind et al., 2010; Tietjen et al., 2018; Wain et al., 2011). For one study of computerised CBT, three of the five participants with MS had a clinically significant reduction in depression scores post-treatment (Tietjen et al., 2018). Another investigation reported a possible moderate effect size of reduction in depression 8 weeks post-treatment (Cooper et al., 2011). The study examining telephone CBT (Wain et al., 2011) reported that only one participant (out of two) completed the intervention, with scores reducing to non-clinical levels at post-treatment, but with a further increase in scores at 6-month follow-up. Another computer-based CBT study reported a significant reduction in depression throughout therapy (Boeschoten et al., 2012).

Overall, there is some evidence to support both telephone and computer-administered CBT for treating depression in pwMS, particularly as they may increase access for pwMS if attending face to face sessions is challenging due to work or family commitments or physical difficulties (Hind et al., 2014). However, it should be noted that results are generally mixed, and some pwMS have reported finding computerised CBT difficult to engage with due to cognitive difficulties and fatigue (Hind et al., 2010).

Group Interventions

A total of eight studies have looked at group-based CBT interventions for depression with pwMS, five of which were RCTs (Forman & Lincoln, 2010; Graziano, Calandri, Borghi, & Bonino, 2014; Larcombeand, Wilson, Larcombe & Wilson, 1984; Lincoln et al., 2011; Pahlavanzadeh,

Abbasi, & Alimohammadi, 2017b). Four showed evidence of a significant decline in depression in the treatment group compared to the control group (Forman & Lincoln, 2010; Larcombeand et al., 1984; Lincoln et al., 2011; Pahlavanzadeh et al., 2017), while Graziano et al. (2014) reported a reduction in depression only at a trend level. Two studies reported that improvements were maintained up to twelve months post-treatment (Forman & Lincoln, 2010; Lincoln et al., 2011).

Of the remaining three studies, two pilot RCTs examined three sessions of group CBT (Rigby et al., 2008) and five sessions of group ACT (Nordin & Rorsman, 2012). These included smaller sample sizes ($n < 50$), and found no significant reductions in depression relative to the control groups. Finally, Masjedi-Araani et al. (2018) adopted a quasi-experimental design to compare group-based CBT, group-based ACT, and a control group receiving only regular consultations. The results showed a significant effect of both CBT and ACT treatments on depression scores, with preliminary evidence showing that CBT may be more effective at reducing depression compared to ACT.

Mindfulness

After CBT, mindfulness represents the second most popular therapeutic approach for depression in MS. A total of eight studies have investigated the efficacy of mindfulness-based interventions on depression in MS (all in a group setting) and one further study has looked at distress as a primary outcome (with depression as a secondary outcome; Bogosian et al., 2015).

Two of the studies targeting depression were RCTs involving active control groups, one of which was delivered online (Cavalera et al., 2018), and the other of which was delivered face to face (Carletto et al., 2017). Sample sizes were relatively large (i.e., 90-156), and the control condition included psychoeducation training (e.g., sleep hygiene, relaxation and stress

management). The interventions generally spanned eight weeks and included homework exercises emphasising daily self-practice to consolidate skills taught in sessions. Both studies reported significant improvements in depression post-intervention, but these gains were only maintained at follow-up in one study (Carletto et al., 2017).

Three additional RCTs with non-active control groups, including treatment as usual (Grossman et al., 2010; Kolahkaj & Zargar, 2015) and a wait-list control group (Simpson et al., 2017), also demonstrated significant improvements in depression post-intervention. However, diminished effects at 3 and 6-month follow-up were reported by both Simpson et al. (2017) and Grossman et al. (2010). Finally, the RCT by Bogosian et al. (2015) using a Skype-delivered adapted MBCT intervention compared to a wait-list control found significant reductions in distress (and depression) post-intervention and at 3-months follow up.

A quasi-experiment of a course inspired by mindfulness-based stress reduction (MBSR) reduced depression in the intervention group but this change was not statistically different from the treatment as usual controls (Crescentini et al., 2018). Finally, two studies adopted an uncontrolled pretest-posttest design to evaluate a mindfulness-based group intervention incorporating yoga and relaxing music (Gilbertson & Klatt, 2017) or MBSR (Blankespoor et al., 2017), and both found a statistically significant improvement in depression.

It should be noted that group content and mode of delivery differed across studies, making the key effective ingredients of the interventions difficult to specify. The presence and amount of daily self-practice and homework also varied considerably, and is arguably difficult to monitor in an objective fashion. In addition, mindfulness-based approaches can be time-consuming and require regular practice of skills in order to be useful. This might explain why effectiveness of interventions tended to tail off at follow-up, as people may become less diligent with skills practice over time without support from a facilitator or therapist. This might

also suggest that booster sessions or explicit guidelines for self-practice should be warranted to maximise treatment efficacy (Simpson, Simpson, Wood, Mercer, & Mair, 2019). Finally, the studies adopting online interventions mentioned regular issues with connection problems, which can cause disruption to sessions (e.g., (Cavalera et al., 2018). Moreover, while arguably increasing access to support, these approaches necessarily exclude people who have no access to the internet.

Other approaches

Four RCTs have investigated alternative approaches to treating depression in pwMS in a group format. These included supportive-expression therapy (with a focus on enhancing emotional expression (Mohr et al., 2001; Mohr et al., 2004); insight orientated therapy (a type of psychotherapy addressing issues around conflict and increasing personal insight; Crawford & McIvor, 1985), and self-management (with a focus on self-efficacy, psychoeducation and relaxation; Barlow, Turner, Edwards, & Gilchrist, 2009). The interventions were generally short-term, with most of them ranging between 5-16 sessions.

The study examining insight-orientated therapy showed evidence of a significant decline in depression scores in the treatment group compared to the control group (Crawford & McIvor, 1985). This was similarly highlighted by the researchers exploring supportive-expression therapy, which reported a significant effect of treatment over time, although the approach was shown to be less effective at reducing depression than individual CBT administered for the same duration (Mohr et al., 2001; Mohr et al., 2003). The study examining self-management only found a trend towards lower depression after the intervention, which was maintained at 12-month follow-up (Barlow et al., 2009).

Eight non-RCT studies evaluated the effects of other group formats on depression in MS. These included positive psychology (e.g., developing strengths and gratitude; Leclaire et al.,

2018), a wellness programme (a biopsychosocial approach aimed at maximising quality of life; McGuire et al., 2015), 'Can Do' treatment (intensive social cognitive treatment; Jongen et al., 2016), dialectical behaviour therapy (DBT; Blair et al., 2017); and integrative therapy spanning a range of approaches including coping, positive psychology, social support and relaxation (Anderson et al., 2017; Bilgi, Ozdemir, Bingol, & Bulut, 2015; Jongen et al., 2016; Kugler, Kruse, & Pöhlau, 2000; Tesar et al., 2003). The interventions were all short term, lasting between 5-10 sessions, except for the 'can do' treatment which adopted an intensive approach across three days (Jongen et al., 2016) and the DBT which was twice weekly for 8 weeks (16 sessions; Blair et al., 2017). Six of these studies found a significant reduction in depression scores following treatment (Bilgi et al., 2015; Blair et al., 2017; Jongen et al., 2016; Kugler et al., 2000; Leclaire et al., 2018; McGuire et al., 2015). The remaining two studies which both focused on integrative therapy, only reported trends of decrease in depression scores over time (Tesar et al., 2003; Anderson et al., 2017).

Further considerations

Groups showing significant reductions in depression scores were generally short-term, varying between 5-10 sessions. This suggests that short-term interventions can help manage depression for pwMS, and a variety of treatment models can be effective. However, as a variety of group models and treatment lengths have been researched it is difficult to determine which model of group therapy is most helpful to participants. Only a limited number of studies used a manualised group programme (e.g., Cavalera et al., 2018; Lincoln et al., 2011; Mohr et al., 2001), thus making replication in a clinical setting challenging. However, it could be argued that studies reflect the real-life conditions in which interventions would be

run in clinical practice, in which treatments are often flexible, human and integrative rather than rigidly manualised.

Fatigue

Fatigue is one of the most common issues associated with MS (Braley & Chervin, 2010), and has been shown to affect up to 90% of pwMS (Strober, 2015; Strober & Arnett, 2005). Fatigue is often reported to be particular debilitating, if not the most significant symptom (Fisk et al., 1994; Krupp & Pollina, 1996; Morrison & Stuifbergen, 2016), as it has been linked to decreased daily activities, increased rates of unemployment, and reduced quality of life (Doesburg et al., 2019; Garg et al., 2016). This can be further exacerbated by difficulties with sleep, which represents another common issue in pwMS (Merlino et al., 2009; Strober, 2015).

CBT

Nine studies adopted CBT to address fatigue in people with MS, seven of which were RCTs. CBT directed at fatigue specifically is often based on a model that suggests that while the disease process causes fatigue, this can be exacerbated by how people react cognitively, emotionally, behaviourally, and physiologically (van Kessel & Moss-Morris, 2006). Programme components include understanding fatigue, activity and rest scheduling, managing stress, identifying and responding to unhelpful thoughts, and managing relapses. They can also focus on improving sleep, problem solving, and social support (van den Akker et al., 2016).

Individual interventions

Six RCTs have evaluated individual CBT interventions for fatigue with pwMS. Van Kessel et al. (2008) reported the first RCT for CBT for fatigue associated with MS comparing an 8-week CBT intervention (3 face-to-face and 5 telephone sessions with an individual psychologist) to relaxation training. Both CBT and relaxation were found to be effective, although the effects

of CBT were greater. Effects were maintained at 6 months, although with decreased effect size for the CBT group. Two further RCTs have looked at individual CBT. One compared 12 sessions delivered in person to three consultations with an MS nurse (van den Akker et al., 2017) while another compared eight sessions administered via phone to an equal number of sessions focused on education on MS (Ehde et al., 2015). Both studies showed improvements in fatigue at post-intervention, but only Ehde et al. (2018) still showed an effect at 12 months. Furthermore, while the effect of CBT was greater in comparison to the nurse sessions (van den Akker et al., 2017), it was not superior to MS education (Ehde et al., 2015). A secondary analysis of Ehde et al. (2015) found that participants with high baseline activation (knowledge, confidence and skills for healthcare) had greater reductions in the CBT group than the education group (Ehde et al., 2018).

Moss-Morris et al. (2012) further developed the van Kessel et al. (2008) materials into 'MSInvigor8', an online programme consisting of eight 25 to 50-minute sessions designed to be accessed by individuals over 8-10 weeks. An RCT with standard care as the comparator, the results showed that fatigue was significantly reduced in the intervention group compared to standard care. Moreover, the importance of the telephone support calls included in the programme was noted by participants (Moss-Morris et al., 2012). MSInvigor8 was trialled in another RCT with and without email support (Van Kessel, Wouldes, & Moss-Morris, 2016), and the results showed that the group with email support showed greater improvements in fatigue than the group without. The attrition analysis in both studies showed that 61% of the telephone support group and 63% of the email support group completed more than half of the sessions, while only 35% did so in the no email group. This suggests that the availability of support measures may play a pivotal role in enhancing participants' engagement. However, although participants' feedback was generally positive, it should be noted that some difficulties with technology were mentioned in both studies, and neither investigation

included a long-term follow-up. Moss-Morris et al. (2012) also conducted an economic evaluation of the programme, and no differences in cost of healthcare use were noted.

Pottgen et al. (2018) similarly studied an internet delivered programme designed for individuals to access over a period of 12 weeks (with advice to access 1-2 times per week) in an RCT. Fatigue was significantly reduced at the end of the intervention and the effects were maintained after 3 months.

Group interventions

Thomas et al. (2010; 2013) developed a group CBT programme for fatigue with a number of other elements (energy effectiveness, self-management, self-efficacy and social-cognitive), 'FACETS', consisting of six 90-minute sessions designed to be delivered by nurses. In the pilot study (2010) only self-efficacy for fatigue was significantly changed after the intervention. However, in the full RCT comparing FACETS to usual treatment (Thomas et al., 2013), the results showed significant improvements for fatigue self-efficacy at 1 and 4 months, for general fatigue severity at 4 months, as well as low attrition and high satisfaction from the participants. Moreover, a 1-year follow-up showed that these improvements were maintained (Thomas et al., 2014).

Wendenbourg et al. (2016) carried out a small uncontrolled feasibility study to evaluate a newly developed group fatigue management programme with a strong CBT component, 'FatiMa', consisting of twice weekly sessions of 90 minutes for 3 weeks. The results showed no significant improvement in fatigue. However, along with the feasibility nature of the study, the authors noted that the intense nature of the programme – designed to fit round inpatient rehabilitation – may have reduced its effect.

Mindfulness

Eight studies adopted mindfulness with pwMS to address fatigue specifically. Of these, only one (Hoogerwerf et al., 2017) included fatigue as the sole primary outcome. The mindfulness interventions tended to be based on established courses (e.g., MBCT or MBSR), although some also incorporated other components.

A large RCT comparing an 8-week mindfulness group (based on MBSR) to usual care (Grossman et al., 2010) found that fatigue improved post-intervention, and that this was maintained at 6-month follow up. Perhaps not surprisingly, the effects were even greater for those with clinically significant levels of fatigue pre-intervention. Similarly, two controlled studies in Iran with younger participants (under age 45) found that MBSR (Alisaleh & Shahrbanoo, 2016) and MBSR combined with conscious yoga (Nejati et al., 2016) significantly improved fatigue at immediate follow up. However, no follow up was conducted and a number of details of these studies are unclear.

Cavalera et al. (2018) developed a Skype-delivered 8-week course also based on MBSR, and compared it against psychoeducation in an RCT. The group comparison showed a change in fatigue in the mindfulness group approaching significance at post-intervention (p = .058), which became fully non-significant at 6-month follow-up.

Hoogerwerf et al. (2017) developed an adaptation of MBCT to target fatigue (e.g., including fatigue-specific psychoeducation and adapted mindful movements; 8 sessions over 10 weeks), and evaluated it with an uncontrolled pretest-posttest design. The results showed that fatigue improved significantly in the participants who completed the intervention (46% of which also showed a clinically significant change), and the benefits were maintained after 3 months. However, it should be noted that 29% of the participants did not complete the intervention.

Another two uncontrolled pretest-posttest studies examining MBSR (Blankespoor et al., 2017) or mindfulness in motion (mindfulness meditation combined with yoga and relaxing music; (Gilbertson & Klatt, 2017) also found improvement in fatigue at immediate follow up. However, Spitzer and Pakenham's (2018) uncontrolled pretest-posttest pilot of a brief (5-week) community-based group mindfulness intervention found no significant improvement in fatigue. The authors argued that this could be due to the exclusion of the mindful movement components from the intervention to allow those with more limited movement to take part. These results were consistent with a previous investigation which removed the mindful movement component for people with primary and secondary progressive MS (Bogosian et al., 2015), and again, found no significant improvement in fatigue. However, it should be noted that in this study fatigue did not constitute a primary outcome for the intervention.

Relaxation

The studies examining relaxation with people with MS mainly targeted fatigue. Three studies looked at relaxation as the experimental condition, whereas two studies had relaxation as the control condition for another intervention.

An RCT examining the effects of muscular and imaginative relaxation in a group setting (practised over 8 weeks) found a reduction in physical but not cognitive fatigue in the intervention group post-intervention (Sgoifo et al., 2017). The proportion of clinically fatigued participants was also reduced and maintained at 6-months. As noted above, van Kessel et al. (2008) compared 8 weeks (3 weeks in person, 5 weeks on the phone) CBT and relaxation for fatigue and both were effective up to six months (although CBT more so).

Carletto et al. (2016) also used an RCT design to compare EMDR with relaxation for participants who had PTSD related to their MS. The results showed significant improvements

in fatigue for both approaches 6 months after the intervention. However, the results of the immediate post-intervention comparisons were not reported.

An uncontrolled pretest-posttest study in Turkey found that practising progressive muscle relaxation from a CD for 6 weeks after receiving a personal one-hour training session significantly reduced fatigue post-intervention (Dayapoğlu & Tan, 2012). An Iranian study also found improvements in fatigue after a 6-week psychological education and relaxation training programme, although many aspects of this study, including the details of the intervention, are unclear (Vazirinejad et al., 2016).

In summary, relaxation may improve fatigue post-intervention but the long-term effects are not clear and may depend on the precise nature of the intervention and how much participants then keep up the practice; one study (van Kessel et al., 2008) suggested CBT may be more effective.

Other approaches

An uncontrolled pretest-posttest study (Anderson et al., 2017) on a group-based manualised self-management intervention combining positive psychology techniques and CBT found that fatigue was significantly reduced post-intervention. However, as the authors note, the outcomes need replicating in a full RCT.

Jongen et al. (2016) carried out an uncontrolled pretest-posttest pilot of an intense 3-day multidisciplinary social-cognitive wellness programme involving people with MS and their support partners ('Can Do' treatment), consisting of multiple elements including small group work, large group work, and joint activities. No significant changes in fatigue were observed up to a year after the programme for either the relapsing-remitting or progressive groups.

Thus, the benefits of these programmes on fatigue remain unclear and need further investigation.

Limitations

This guidance mainly focuses on the primary outcomes of studies. However, as fatigue represents one of the most common and debilitating symptoms of MS, it is not surprising that it is included in a large number of studies as one of several general outcomes for pwMS. As a consequence, several studies reported changes in fatigue within the context of interventions targeting other constructs in pwMS. Examples include positive effects on fatigue observed when adopting CBT for depression (Fischer et al., 2015; Kiropoulos et al., 2016; Mohr et al., 2007; Mohr, Hart, & Goldberg, 2003) or no effects when adopting mindfulness for mood and quality of life (Bogosian et al., 2015). However, the precise nature of the relationship between fatigue and depression in MS remains to be clarified further (e.g., Mohr et al., 2003) and therefore such findings from secondary outcomes are currently only tentative. Multiple component programmes have only been included here where there was a strong psychological component. Thus, programmes which focused mainly on physical components (e.g., energy conservation) have not been included.

Hope and optimism

Hope and optimism both relate to positive expectations about the future (Alarcon et al., 2013). Hope has been formally conceptualised as a combination of perceived successful agency and perceived availability of successful pathways to achieve a goal (Snyder et al., 1991). Optimism, on the other hand, relates more generally to positive outcome expectancies (Scheier & Carver, 1985). Thus, the optimist believes that somehow the future will work out well, whereas the hopeful person believes that their capabilities and actions will lead to this

goal (Alarcon et al., 2013). Despite these theoretical differences, both can be viewed as personal resources (Alarcon et al., 2013) and have been associated with adaptive coping (Carver et al., 2009; Rand & Cheavens, 2009). Higher levels of hope have been associated with greater self-esteem, higher social support (Foote et al., 1990) and lower depression (Lynch et al., 2001) and predicted better adjustment (Madan & Pakenham, 2014) in pwMS. Optimism has been associated with lower depression and benefit finding (Hart et al., 2008). Three studies have included hope and two have included optimism as one of their main outcomes.

The studies on hope included one RCT of supportive expressive therapy (abolghasemi et al., 2016), one quasi-experiment comparing a group self-management programme with the provision of self-management brochures (Feicke et al., 2014) and one pretest-posttest study of a self-management intervention combining positive psychology techniques and CBT (Anderson, Turner, & Clyne, 2017). All found their interventions increased hope at immediate follow up.

The studies on optimism were less clear. LeClaire et al. (2018) adopted a pretest-posttest design to pilot a positive psychology intervention but found no change on a measure of optimism. Calandri et al. (2017) carried out a quasi-experiment with newly diagnosed pwMS to compare a group-based CBT intervention with treatment as usual. At 6 months the comparison group had increased in optimism more than the intervention group but at one year, the CBT group had maintained their optimism from six months whereas the comparison group's deteriorated. The groups were not evenly matched at baseline though so the impact on optimism needs further study.

Pain

Pain is reported to be a common symptom for pwMS (Stenager et al., 1991), with prevalence rates ranging from 57% to 86% (O'Connor et al., 2008). Due to the varied location of lesions in MS, pain can present in a variety of ways and is known to have a significant impact on daily life for pwMS, affecting both physical and emotional functioning (Harrison et al., 2015; Jensen et al., 2007; Svendsen et al., 2005).

Only one RCT (Ehde et al., 2015) has so far focused on pain in people with MS (along with depression and fatigue), and the psychological literature concerning pain and MS appears to be rather limited, with only three additional studies retrieved. Of these, one was an uncontrolled pretest-posttest design (Jensen et al., 2011), one a case-series (Rona Moss-Morris et al., 2017), and one a case report (Dane, 1996).

CBT

The one RCT has examined telephone-based CBT, over eight weekly sessions of 45-60 minutes, but reported no significant effect on pain when compared to a control group receiving psychoeducation (Ehde et al., 2015). Both groups showed a statistically significant reduction in pain after treatment which was sustained at 6 and 12 months. Harrison et al. (2017) used an 8-week hybrid CBT/ACT self-management workbook programme ('Guided cognitive behavioural self-management treatment for MS pain, GIFT') with seven people with MS, along with semi-structured qualitative telephone interviews to investigate experiences of the treatment. Three participants showed significant improvements in pain outcomes, two showed no change and two worsened. Five participants showed significant changes on pain catastrophising, negative emotional representations of pain, beliefs about chronicity and negative consequences, avoidance of social activities and, to a lesser extent, pain acceptance.

Change in pain catastrophising was the most consistent finding. All participants found the programme beneficial, but only three reported significant improvements in pain outcomes, and five in psychological processes.

Hypnosis

Jensen et al. (2011) adopted a treatment programme for chronic pain consisting of four modules: (a) an education control intervention; (b) self-hypnosis training (HYP); (c) cognitive restructuring (CR); and (d) a combined hypnosis-cognitive restructuring intervention (CR–HYP). Assessment points were placed after each module. The results showed greater beneficial effects of HYP, relative to CR, on average pain intensity. CR–HYP had beneficial effects greater than CR and HYP alone.

Dane et al. (1996) adopted hypnotic imagery and posthypnotic suggestion with a 30-year-old patient with RRMS, who was asked to keep a daily pain log for two weeks. The results showed improvement in control of pain, along with sitting balance and diplopia (double vision) and return to ambulatory capacity post-treatment.

Given the limited research in pain thus far, caution is advised when interpreting the results.

Personality and identity

Two further studies targeted very specific outcomes relating to temperament, personality and identity.

Crescentini et al. (2018) studied a programme based on MBSR, using a quasi-experimental design and assessed changes in temperament with the temperament and character inventory (Cloninger et al., 1994), and personality with the Big Five Inventory (Costa & McCrae, 1992). They found significant increases in character traits reflecting the maturity of the self at the

intrapersonal (self-directedness) and interpersonal (cooperativeness) levels, in meditation group but not in the control group. There was also significant increase in conscientiousness in the intervention group but not control group. No changes in agreeableness, neuroticism, extraversion and openness were found.

In an RCT, Graziano et al. (2014) compared group CBT with information sessions. Changes in identity were assessed using the Identity Motives Scale (Manzi et al., 2010) which assesses expectations of how an individual will feel in the future and sense of the coherence was assessed with the Italian version of the Sense of Coherence (SOC) scale (Barni & Tagliabue, 2005). SOC is a global personality trait which facilities adaptive coping. It is based on the theory of Antonvosky (1987) and the scale assesses three concepts: comprehensibility (whether individuals can predict events in their environment); manageability (whether an individual's actions can fulfil their needs); and meaning (the capacity to find aspects of the environment worthy of personal investment; Flannery, Perry, Penk, & Flannery, 1994). There was no difference between the intervention group and control group post treatment or at 6-months.

Positive and negative affect

Positive and negative affect are dispositional dimensions whereby negative affect indicates the degree of distress and unpleasurable engagement with the environment, incorporating mood states such as anger, disgust, guilt and fear. Positive affect indicates pleasurable engagement with the environment where an individual is enthusiastic, active and alert (Watson et al., 1988). The two are viewed as separate factors although in one of the most common measures, the positive and negative affect schedule (PANAS; Watson et al., 1988), they are moderately negatively correlated (Crawford & Henry, 2004). Nonetheless each explain a unique portion of variance in depression measures, with more unique variance

explained by positive affect (Crawford & Henry, 2004). Greater positive affect has also been related to greater benefit-finding at a later time point for pwMS (Hart et al., 2008).

Only one RCT had positive affect as one of the main outcomes (Mohr et al., 2005). The other studies including one quasi-experiment (Calandri et al., 2017) and four pretest-posttest studies (Anderson et al., 2017; Gilbertson & Klatt, 2017; Leclaire et al., 2018; Sinclair & Scroggie, 2005) had positive and/or negative affect measured as part of a range of outcome measures, where the primary outcome was not stated. The findings were quite mixed.

CBT

Mohr et al.'s (2005) RCT of telephone CBT versus supportive emotion-focused therapy found greater improvements in positive affect for CBT post-intervention (negative affect was not measured). Gains were maintained at 12 months although no group differences were seen at this point.

One group CBT study found significant decrease in negative affect but increases in positive affect at a trend level only at immediate follow up (Sinclair & Scroggie, 2005), while another found short- (6 month) but not long-term (1 year) effects on negative affect and no changes in positive affect when compared with the control group (Calandri et al., 2017).

Mindfulness

Gilbertson et al. (2017) assessed the feasibility of an 8-week Mindfulness in Motion programme (incorporating yoga and relaxing music with meditation) and found significant increases in positive affect (negative affect was not measured).

Other approaches

Anderson et al. (2017) looked at a group-based intervention combining positive psychology techniques and CBT and found a significant increase in positive affect but no change in negative affect. However, Leclaire et al.'s (2018) positive psychology intervention found no significant changes in either positive or negative affect.

Psychosocial difficulties

As previously discussed, due to the age of onset of MS and the unpredictability and changeability of the course of the illness, a wide range of psychological and social factors can be impacted. Psychosocial difficulties are an umbrella term that refers to the biopsychosocial difficulties that shape the experience of a person and encompasses physical, neurocognitive and psychological factors (Cieza et al., 2013; Giovannetti et al., 2016; Tompkins et al., 2013). PwMS report difficulties due to motor functions, emotional functions and sleep, alongside difficulties with work, and relationships that impact well-being and quality of life (Giovannetti et al., 2016; Raggi et al., 2016; Sheppard et al., 2010).

Two studies reported on psychosocial difficulties in people with MS (Sheppard et al., 2010; Tompkins et al., 2013). However, as with other multifactorial constructs (cf. adjustment), their conceptualisation was not consistent across the investigations.

Sheppard et al. (2013) adopted ACT in a half-day workshop intervention in an uncontrolled pretest-posttest design, and used a number of different measures including depression, fatigue, pain and quality of life. At 12-week follow-up, improvements were reported for depression, thought suppression, impact of pain and quality of life.

Tompkins et al. (2013) developed 'Relationship Matters', a relationship enrichment programme designed for couples living with MS, and assessed it in a quasi-experiment against

MS couples receiving no treatment. Significant improvements were observed on relationship satisfaction and mental health-related quality of life. Reported improvements also included communication, conflict resolution, and ability to handle MS-specific relationship issues.

Quality of life and well-being

Quality of life has been conceptualised as a measure of well-being (Nery-Hurwit et al., 2018) and is a multi-faceted construct that encompasses aspects of living such as physical, emotional, social and spiritual well-being that influences goals, expectations and standards (Kes et al., 2013; Ysrraelit et al., 2018). MS has been reported to impact significantly both physical and emotional quality of life, and pwMS report lower quality of life compared to the general population and people with other long-term health conditions (Gedik et al., 2017; Holmes et al., 2012; Klevan et al., 2014; Ysrraelit et al., 2018). This pattern has been demonstrated even for people who are newly diagnosed (Pugliatti et al., 2008). Therefore, factors such as resilience, stress and self-esteem have been concepts that have been studied in relation to quality of life for pwMS (Mikula et al., 2017; Rainone et al., 2017; Senders, Bourdette, Hanes, Yadav, & Shinto, 2014).

CBT

Four studies adopted CBT interventions to address quality of life and well-being in pwMS. Graziano at al. (2014) compared group-based CBT to generic informative sessions with an RCT. The results showed significant improvements in quality of life at six months for the intervention group, and a significant increase in well-being was observed for male participants. However, well-being scores for female participants showed a slight decrease over the same time period.

Calandri et al. (2017) carried out a quasi-experiment to compare a group-based CBT intervention with participants receiving no treatment. The results showed significant improvements in the mental health component of the SF-12 (a commonly-used quality of life scale; Ware, Kosinski, Keller, Care, & Mar, 1996) at both post-intervention and 1-year follow-up. However, no significant changes were observed at either time points for the physical health component.

Mohr et al. (2005) carried out an uncontrolled pretest-posttest study to assess a CBT-informed skill-based individual telephone-administered peer support programme. The results showed a significant improvement for overall QoL, along with significant improvements in depression, environmental mastery, positive relationships with others, and purpose in life. A trend-level improvement in autonomy was also observed. Another uncontrolled pretest-posttest study of a group-based programme with CBT components called "beyond MS", which involved five 2-hour sessions, found increases in psychological well-being (Sinclair & Scroggie, 2005).

Mindfulness

Seven studies used variants of mindfulness (Agland et al., 2018; Cavalera et al., 2018; Grossman et al., 2010; Nejati et al., 2016; Spitzer & Pakenham, 2018), of which four were RCTs (Agland et al., 2018 ; Cavalera et al., 2018 ; Grossman et al., 2010; Nejati et al., 2016). The results from all the investigations showed some improvement in quality of life, although the specifics of the results show a more nuanced account. For example, Cavalera et al. (2018) reported improvements in quality of life immediately after intervention, but no improvements against the psychoeducation control group at six months. On the other hand, Grossman et al. (2010) reported further improvements from immediately post-intervention to six months post intervention. Nejati et al. (2018), Gilbertson and Klatt (2017) and Spitzer et al. (2018) all reported improvement on most quality of life domains, but not all. The qualitative analysis

from the latter also showed that the participants reported benefits in present moment awareness, coping skills, self-compassion, acceptance, support, and change of perspective.

Other interventions

Three other studies (Abolghasemi, Taherifard, Farhang, Kiamarsi, & Saharkhiz Arabani, 2016; Jongen et al., 2016; Leclaire et al., 2018) used other approaches (supportive expressive therapy, 'Can do', and positive psychology respectively) and were generally successful in improving quality of life using standardised scales.

Limitations

Despite being constructs with a relatively consistent definition, quality of life and well-being were operationalised in a number of ways. Of the studies measuring quality of life with a specific measure, six used a generic tool, one used a chronic illness specific scale and seven used a MS specific tool. One study (Grossman et al., 2010) used both a chronic disease and a MS specific measure. Moreover, as some with other constructs (cf. fatigue, sleep), some studies reported results on quality of life within the context of interventions aimed primarily at other outcomes. For instance, Cosio et al. (2011) performed a secondary analysis of an RCT for depression comparing telephone-administered CBT (T-CBT) with telephone-administered supportive emotion-focused therapy (T-SEFT). The results showed significantly greater improvements in QoL for the T-CBT group, which were significantly mediated by improvements in depression and positive affect, thus suggesting a superior efficacy of T-CBT procedures specific to the management of depression and positive affect.

Self-efficacy

Self-efficacy has been conceptualized as belief and confidence in the ability to cope successfully with the challenges that one faces (Schmitt et al., 2014; Tan-Kristanto & Kiropoulos, 2015; Teasdale, 1978). MS presents many challenges that need to be managed throughout the course of the illness. For pwMS, self-efficacy has been shown to have a positive impact on quality of life, positive adjustment and physical and social functioning (Amtmann et al., 2012; Eccles & Simpson, 2011; Mohr, Boudewyn, Likosky, Levine, & Goodkin, 2001; Motl, McAuley, Wynn, Sandroff, & Suh, 2013; Schmitt et al., 2014). Seven studies developed interventions aimed at enhancing self-efficacy in people with MS. Jongen et al (2016) and Anderson et al. (2017) adopted an uncontrolled pretest-posttest design, Feicke et al. (2014) adopted a quasi-experimental design and the rest were RCTs.

CBT

One study (Graziano et al., 2014) adopted group-based CBT and compared it to basic informative sessions. The results showed a significant increase in self-efficacy in the intervention group at post-treatment when compared with controls, but not at the 6-month follow-up, thus suggesting a short-term effect of the intervention.

Rigby et al. (2008) used a form of group psychotherapy focused on cognitive appraisals, coping resources, and coping strategies coupled with educational material produced by the MS society, and compared it to the combination of education material and non-structured social discussions, and education material alone. The results showed significant benefits in self-efficacy for the psychotherapeutic and social discussion groups compared to educational material only, but no significant differences between psychotherapy and social discussions.

Therefore, much of the benefit of these group interventions may derive from non-specific therapeutic components, such as being part of a group.

Self-management

Barlow et al. (2009) compared a Chronic Disease Self-Management Course (CDSMC) to no treatment, and found a significant positive impact on generic self-efficacy at both post-treatment and 12 months. However, benefits for MS-specific self-efficacy were at trend level only. Hemmati et al. (2014) also adopted a self-management programme, and found a significant difference in self-efficacy between the intervention group and controls at post-treatment. Feicke et al (2014) compared a 5-session group self-management programme for pwMS with the provision of self-management brochures covering the same content and found an increase in self-efficacy for the self-management group. Finally, Anderson et al., (2017) used a group-based manualised self-management intervention combining positive psychology techniques and CBT found that self-efficacy improved post-intervention.

Other approaches

Jongen et al. (2016) adopted a 3-day social cognitive programme aimed at uncovering and promoting existing capabilities ('Can Do' treatment) and characterised by a number of components including (1) large group sessions, (2) small group sessions, (3) consultations, (4) a theatre evening, and (5) start of the day with a joint activity. The results showed a significant increase in self-efficacy (20.2%) for people with RRMS. However, the assessment points were only at baseline and 12 months, and no significant improvements were observed in people with PPMS.

Limitations

As observed with other constructs (cf. adjustment, quality of life, stress), self-efficacy presented a wide range of operationalisations across the studies. In particular, three investigations (Anderson et al., 2017; Jongen et al., 2016; Rigby et al., 2008) adopted the MS self-efficacy scale (MSSES), one (Barlow et al., 2009) the MS-specific Liverpool Self-Efficacy Scale, two (Graziano et al., 2014; Hemmati Maslakpak & Raiesi, 2014) an unspecified ad-hoc self-efficacy scale for MS, while Feicke et al. (2014) used a subscale of the self-management scale (Jack, 2007). While most of the studies adopted MS-specific tools to assess self-efficacy, such inconsistency in the operationalisation of self-efficacy represents a limitation to the generalisability of the results.

Self-esteem

Global self-esteem has been conceptualised as an individual's global, subjective and emotional evaluation of their perceived worth as a person (Rosenberg, 1965). It is unclear whether people with MS experience lower self-esteem generally than the population as studies have conflicting findings and may depend on the precise sample (McCabe, 2005; Messmer Uccelli, Traversa, & Ponzio, 2016). However, theories of psycho-emotional disablism suggest for those with physical and cognitive difficulties, living in a society where they frequently experience stigma and discrimination is likely to lead to lowered self-esteem (Thomas, 2007) and qualitative findings point to a changing relationship with the self and possible loss of self-worth for some (Mozo-Dutton et al., 2012). Greater self-esteem has been associated with greater social participation, greater social support, higher ratings of mental and physical components of quality of life, use of more adaptive coping strategies and lower perceived stress in pwMS (Dlugonski & Motl, 2012; Ifantopoulou et al., 2015; Mikula et al., 2017, 2018).

Only two studies have looked at self-esteem as a main outcome. Robati and Shareh's (2018) controlled study in Iran studied group CBT and found significant improvements in levels of self-esteem compared to the waiting list control group. In another controlled study Crawford and McIvor (1985) compared insight-oriented psychotherapy with a group that discussed current events and a no treatment group. No differences in self-esteem were found between the groups.

Sleep

Difficulties with sleep have been estimated to impact up to 60% of pwMS (Braley & Chervin, 2010; Sakkas et al., 2019). Poor sleep has been linked to reduced quality of life (Marrie, Reider, et al., 2015). Despite this, sleep problems are under-recognised and under-treated (Sakkas et al., 2019). The most common sleep difficulties experienced by people with MS are obstructive sleep apnoea, insomnia, sleep-related movement disorders, and circadian rhythm disorders (Braley & Chervin, 2010; Marrie, Reider, et al., 2015; Sakkas et al., 2019). Fatigue is thought to be the most common symptom of MS, impacting >85% of people (Minden et al., 2006), and has a significant impact on quality of life (Amato et al., 2001). Although fatigue itself is linked to the underlying neurological changes rather than poor sleep (Braley & Boudreau, 2016), poor sleep has been associated with exacerbating fatigue (Lobentanz et al., 2004; Marrie, Reider, et al., 2015). Six studies have developed interventions to target sleep difficulties in pwMS, two of which (Abbasi, Alimohammadi, & Pahlavanzadeh, 2016; Cavalera et al., 2018) were RCTs.

Abbasi et al. (2016) compared eight sessions of CBT with a number of sleep specific components with three general sessions focused on feelings and personal experiences. The results showed a significant improvement in sleep in the CBT group at post-intervention, and benefits were maintained at 1-month follow-up. Cavalera et al. (2018) developed a group

online MBSR intervention and compared it to a psychoeducation group. Results on sleep measures showed significant improvements in the MBSR group at post-intervention, but these effects were not maintained at 6 months.

Dayaploglu and Tan (2012) adopted an uncontrolled pretest-posttest design to evaluate a 6-week progressive muscle relaxation programme consisting of a personal 1-hour training session combined with home exercises administered by CDs. The results showed a significant improvement for sleep at post-intervention (Dayaploglu & Tan, 2012).

Three investigations reported data from case studies. Clancy et al. (2015) carried out a retrospective case series of 11 people who had participated in at least two sessions of individual or group-based CBT for insomnia (CBT-I) and found that two out of three with SPMS and six out of eight with RRMS reported an improvement in their total sleep time (Clancy et al., 2015). Moreover, of the seven participants for whom questionnaire data were available, two individuals with SPMS and four with RRMS reported an improvement in sleep. Similarly, Majendie et al. (2016) reported a case study where (CBT-I) was adopted with an individual with SPMS, finding an improvement in sleep and reduction in sleep medication to zero which was maintained up to the 7-month follow-up. Another case example using CBT with a relaxation component and hypnosis for a woman with considerable pain and physical limitations reported substantial improvements in her sleep (Slatter, 2016). However, these improvements are difficult to quantify as no standardised measures were adopted.

Thus CBT, particularly with sleep specific components, may be a promising intervention for further investigation in RCTs and mindfulness and relaxation may also be worthy of further study, particularly to see if benefits can be maintained long-term.

Limitations

Due to its subjective nature, sleep represents a difficult construct to measure and all studies here relied on self-report (whether just noting participants' report of improvements or on standard measures). Sleep has also been measured as a secondary outcome in interventions which were not designed to address sleep difficulties in the first place. For example, secondary analysis of an RCT comparing a CBT telephone-delivered intervention for depression with supportive emotion-focused therapy (Baron et al., 2011), found that both interventions reduced the proportion of people with sleep problems, and that decreases in insomnia were related to decreases in depression and anxiety. However, as mentioned with other constructs (cf. fatigue), any conclusions from interventions targeted at constructs other than sleep need to be viewed with caution where mechanisms are not fully understood.

Stress

Stress has been defined as actual or perceived threats to a homeostatic state, encompassing both environmental threats and psychological responses (Artemiadis et al., 2011; Lovera & Reza, 2013) and is known to have both physiological and psychological components. Stress has been shown to have an important role for pwMS. PwMS commonly report that they feel stress exacerbates their symptoms (Ackerman et al., 2002; Angela Senders et al., 2016), and research evidence supports a positive association between stress levels and MS symptoms (Artemiadis et al., 2011; Mohr, Hart, Julian, Cox, & Pelletier, 2004). Some evidence has suggested stress can contribute to MS relapses (Ackerman et al., 2002; Artemiadis et al., 2011; Mitsonis et al., 2009), increases lesion activity on MRI (Burns, Nawacki, Kwasny, Pelletier, & Mohr, 2014; Mohr et al., 2000) and may play a role in onset of MS (Li et al., 2004). Management of stress is therefore an important treatment consideration.

Nine studies have explored interventions to help manage stress in people with MS. Five were RCTs (Agland et al., 2018; Kolahkaj & Zargar, 2015; Pahlavanzadeh et al., 2017; Senders et al., 2018; Simpson et al., 2017), one was a quasi-experiment (McGuire et al., 2015), and three adopted an uncontrolled pretest-posttest design (Pritchard, Elison-Bowers, & Birdsall, 2010; Spitzer & Pakenham, 2018; Tietjen & Breitenstein, 2017).

CBT

Only one study (Pahlavanzadeh et al., 2017) used traditional CBT. The intervention, specifically aimed at women with MS, consisted of a group format using the ABCD model: A) Existence of a reality, event or behaviour, B) Belief, C) Emotional and behavioural consequences D) Challenging and confronting the thoughts. The results showed a significant decrease in stress in the intervention group at post-test and one month.

Mindfulness

Six studies used mindfulness or meditation-based interventions, such as mindfulness-based stress reduction (MBSR; Kolahkaj & Zargar, 2015; Senders et al., 2018; Simpson et al., 2017) and Yoga Nidra meditation (Pritchard et al., 2010), as well as stress management programmes inspired by MBSR or mindfulness-based cognitive therapy (MBCT; Agland et al., 2018; Spitzer & Pakenham, 2018). The majority of the findings showed a significant improvement in perceived stress for the intervention groups, and further qualitative evaluations showed good feasibility and acceptability for MBSR in people with MS (Simpson, Byrne, Wood, Mair, & Mercer, 2018). However, the evidence on improvements in perceived stress was in some cases limited to the short term either due to study design limitations (Spitzer et al., 2018), or due to considerable decrease of effect sizes at follow-up (Simpson et al., 2017). In addition, Agland et al. (2018) failed to observe any significant improvement in perceived stress in the intervention group, while Senders et al. (2018) found significant improvements in the

intervention group, but no significant differences when compared to controls who were provided with MS Education pamphlets published by the National MS Society.

Other approaches

McGuire et al. (2015) adopted a psychoeducational MS wellness group programme based on the biopsychosocial model of disease. The results showed significant improvements in perceived stress in the treatment group, along with depression, anxiety, overall mental health, and pain.

A small study using motivational interviewing approach via telephone to help participants reach their goals (Tietjen & Breitenstein, 2017), found that 90% chose to target stress and most participants made some progress towards their goals but there were no other formal measures administered.

Limitations

Due to its multifactorial nature, and similarly to other constructs (cf. adjustment, quality of life, self-efficacy), the operationalisation of stress was limited by a wide and rather inconsistent range of measures and methods. The most common measures were the Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) and the stress subscale of the Depression, Anxiety, and Stress Scale (DASS; Lovibond & Lovibond, 1995), adopted by six and four studies respectively, while one study (Agland et al., 2018) adopted a stress visual analogue scale (sVAS).

General comments for interventions for MS

Both individual and group approaches have been found to be effective for a range of outcomes in MS. PwMS have generally reported that they find group-based interventions to

be an acceptable therapeutic format (Leclaire et al., 2018; Tesar et al., 2003). Groups also tend to be less resource demanding than individual therapy (Fernie et al., 2015) and can help reduce waiting times (Firth, 2014). One study has looked at the cost benefits of group treatment for pwMS and depression (Humphreys et al., 2013), and reported a reduction in treatment costs of £378 per respondent. This is an important consideration for many services, where clinicians often have limited time, resources are stretched and demands are high for therapy input. Short-term group programmes may therefore be a cost-effective way to ensure that more pwMS are able to access evidence-based treatments. However, one study which examined attendance at groups for pwMS (Holmes et al., 2012) highlighted the challenges associated with attending groups during typical working hours (Graziano et al., 2014), and showed how male participants were also less likely to attend the group programme. Attendance is a particularly important consideration, as, perhaps unsurprisingly, increased attendance can affect the effectiveness of the therapy (Holmes et al., 2012).

Another consideration is whether all approaches are suitable for all subtypes of MS. Studies have predominantly included people with diagnoses of RRMS and SPMS, making it difficult to conclude whether certain types of therapy are more or less useful or appropriate for specific subtypes of MS. Only one study examined differences in treatment outcomes between people with RRMS and SPMS (Jongen et al., 2016), showing a significant effect for people with RRMS, but not those with SPMS. This suggests that not all group-based treatments may be equally effective for people living with different MS subtypes.

Accessibility is also an issue that needs to be considered as attending in person may not be possible for all and home visits may be needed. While telephone and computer-based treatments can improve access, some people find computerised CBT too difficult due to cognitive difficulties and fatigue (Hind et al., 2010) and for one study with no additional human

support only 35% completed at least half the sessions (van Kessel et al., 2016). Thus, computerised interventions are clearly not suitable for all.

Access to psychology services

Health Improvement Scotland (2019) recommends people with neurological conditions should receive coordinated person-centre care involving a holistic assessment of a person's needs including psychological and emotional needs. Similarly, NHS Wales Neurological Conditions Delivery Plan (2017) highlights the need for holistic approaches including psychological and emotional well-being and the need for integrated and coordinated care. More specifically for MS, NICE guidelines for MS (2014) recommend that care for people with MS should be via a multidisciplinary approach with one person coordinating the care. NICE guidelines recommend that pwMS have a comprehensive review at least once a year of all symptoms and difficulties and that this should include a review of difficulties with anxiety, depression, sleep, fatigue and pain and that if issues are noted that the person should be referred to an appropriate professional. The guidelines do not specifically mention psychological approaches for depression or anxiety but refer to the general guidelines for managing depression in people with long-term health conditions (NICE, 2009b) and general guidelines for managing anxiety in the general population (NICE, 2011). However they do note that pwMS with fatigue should be assessed and given access to psychological support for anxiety, depression and sleep difficulties (which may be impacting on the fatigue) and in particular mention mindfulness-based therapies, CBT and fatigue management as possible approaches to help fatigue.

NICE guidelines for the general population for chronic health conditions (2009) state that treatment for depression should follow a stepped care model. Thus, depression will usually

be highlighted in primary care services as a first step, where the pwMS can be initially assessed and monitored, and referred onto an appropriate service for further assessment and intervention. Low-intensity psychological interventions (computerised CBT, group-based peer support, or self-help based on CBT principles) are recommended for mild to moderate depression, alongside physical activity programmes and psychoeducation. High-intensity interventions (group or individual CBT, or behavioural couple therapy) are advised for severe or complex depression, or mild to moderate depression that has not responded to low-intensity intervention. Antidepressant medications (generally SSRIs) may be offered in conjunction with psychological interventions for more refractory or severe presentations of depression.

While there are no guidelines specific to MS or long-term conditions and anxiety, guidelines for the general population highlight a similar stepped care model for treatment of generalised anxiety disorder (NICE, 2011). This also suggests initial identification and assessment as a first step, initially followed by low-intensity treatment, and high intensity treatment for people who do not respond to low-intensity interventions, and for those with complex presentations, high levels of risk or very marked functioning impairment. Again, low-intensity treatments will comprise individual self-help, guided self-help, or psychoeducational groups – all based on CBT principles. High intensity input involves the patient choosing between CBT or applied relaxation, lasting twelve to fifteen weeks, alongside potential pharmacological treatments (usually SSRIs).

Accessing help for psychological difficulties for a person living with MS, their clinical nurse specialist or GP will be the first point of contact for any concerns. Access to either a neuropsychologist or psychologist via a local neurological service is very variable across the UK. A referral to a mental health service such as Improving Access to Psychological Therapies

(IAPT) in England will often be suggested to help with feelings of depression and anxiety in the first instance (Methley et al., 2017). IAPT services provide short-term CBT. IAPT services usually take self-referrals, meaning a person can make the referral themselves and they do not need to go through a GP or health professional. However, surveys by the Neurological Alliance of people with neurological conditions in England (2019) suggested that accessing such services could be difficult or even when accessed, healthcare professionals did not have the relevant expertise to help. While it is unclear to what extent this applies specifically to pwMS, one small study of pwMS, GPs, practice nurses and specialist nurses in the North West of England (Methley et al., 2017) suggested that accessing appropriate mental health support could be problematic. The nurses did not feel confident dealing with mental health needs and could feel stuck as there was no specialist mental service to which pwMS could be referred and eligibility for generic mental health services was variable. While a few GPs and specialist nurses suggested that services were good and well-coordinated, the majority reported that waiting lists were long and service provision geographically variable with no psychological services offering home visits which were required for those with mobility problems. A small study in Wales has also highlighted the lack of psychological support, particularly around the transition from RRMS to SPMS (Davies et al., 2015). The 'My MS My Needs' Survey by the MS Society (Redfern-Tofts, McDougal, & McDougal, 2016) suggested that 21% of people in the UK wanted more support for mood and emotional issues (ranging from 20% in England to nearly 28% in Wales). Thus, further work is needed to improve collaborative working and pathways and to improve staff skills (e.g., of mental health professionals) to meet the psychological needs of people with MS.

Organisations and charities

MS Society

The MS Society (https://www.mssociety.org.uk/) was founded in 1953 and is a charity that aims to provide a community for pwMS. The MS society runs support groups across the UK, and details of local support groups can be found on their website (https://www.mssociety.org.uk/care-and-support/local-support). The MS Society also provides a free helpline (0808 800 8000) that provides emotional support to pwMS.

MS Trust

The MS Trust (https://www.mstrust.org.uk/) was founded in 1993 and is a charity dedicated to helping pwMS. Their website contains information to help pwMS to find local independent support groups (https://www.mstrust.org.uk/a-z/support-groups). Their website also contains a list of online forums and online support groups that pwMS can join to discuss and share experiences.

MS-UK

MS-UK is a charity which was founded in 1993 and offers a telephone counselling service for pwMS, with counsellors that are BACP accredited. A person can register their interest in telephone counselling online at their website (https://www.ms-uk.org/counselling), or a health professional can make a referral on their behalf via the website. There is also a helpline for additional queries (0800 783 0518).

MS National Therapy Centres

There are over 60 MS National Therapy Centres across the UK, each forming an individual local charity to help pwMS (https://www.msntc.org.uk/). Some MS National Therapy Centres can

offer counselling services. Local centres can be found through the MS National Therapy Centres website, and self-referrals are accepted.

Action MS

Action MS is charity which aims to provide practical support to those living with MS in Northern Ireland and their families. They have several support services including advocacy, family support and counselling as well as providing education, user-led groups and education for professionals. See http://www.actionms.co.uk/our-services/ for more details.

Shift MS

Shift MS provides a social network for people with multiple sclerosis. The charity supports many thousands of recently diagnosed people across the world as they make sense of MS. See https://shift.ms/about-us for more details.

Lancaster University

CONCLUSIONS

Summary of findings

Huntington's disease

For HD there has been very little research into psychological interventions. Alongside the case studies, there was only one non-randomised group study for individuals who did not need residential care (A' Campo et al., 2012) which looked at an education programme for pre-manifest and manifest individuals. This found some benefits on several outcomes, although generally more for manifest than pre-manifest individuals and not everyone completed the programme. One further RCT looked at relaxation and sensory stimulation for those in a specialist residential unit (Leng et al., 2003) and found no difference between the groups but the study was small. Hence, no conclusions can be offered yet as to which psychological interventions may help people with HD.

Parkinson's disease

More research has been conducted with pwPD than pwMND or pwHD. One large RCT has shown depression to be reduced by individual CBT (Dobkin et al., 2011). This positive finding has largely been reproduced in other smaller RCTs and non-RCT studies, including ones which used group-based or telephone-delivered interventions. Most of the mindfulness studies also reduced depression at immediate follow up, as did a psychodrama intervention (Sproesser et al., 2010), but neither of the psychoeducation interventions studied showed effects on depression levels (Guo et al., 2009; Macht et al., 2007).

Interventions targeting anxiety with CBT (individually in person, in a group or by phone) had mixed outcomes, but many studies had small samples; however, some studies did have positive findings which were sustained up to 6 months (e.g., Dissanayaka et al., 2017; Troeung et al., 2015). Mindfulness-based interventions often (but not always) improved anxiety, with

effects lasting up to 6 months in one non-RCT study (Dissanakaya et al., 2016). A psychodrama intervention also reduced anxiety in an RCT (Sproesser et al., 2010). Relaxation as an intervention on its own has only been studied in two case studies.

Studies using CBT (two RCTs; Hadinia et al., 2016; Troeung et al., 2014) and mindfulness (two non-RCTs: Birtwell et al., 2017; Dissanayaka et al., 2016) have both generally found reductions in stress which have sometimes been sustained at longer term follow up.

Outcomes for both CBT and mindfulness for improving quality of life were mixed. In addition, a group body awareness training based on ACT (Ghielen et al., 2017), a psychodrama intervention (Sproesser et al., 2010) and one education programme (Guo et al., 2009) found improvement in quality of life but another education programme studied in several countries (Macht et al., 2007) did not. Considering psychosocial issues, one RCT investigating a group psychoeducation programme compared to usual care for pwPD undergoing deep brain stimulation found that the groups did not differ on social adjustment at 1 year but did at the 2-year follow up (Santos et al., 2017). One CBT education programme found no change in psychosocial stress (Tiihonen et al., 2012), but another education programme led to improvements in psychosocial issues (Macht et al., 2007). Behavioural relaxation training and self-focused exposure therapy (SFET) were investigated for psychosocial issues in case studies only.

All the interventions which targeted sleep and incorporated CBT, including RCTs on a multicomponent sleep therapy (Leroi et al., 2010) and CBT for insomnia (CBTi) plus light therapy (Romenets et al., 2013), improved some aspects of sleep. Computerised CBTi improved sleep for those who completed the intervention when compared to controls, but only 57% completed it (Patel et al., 2017).

CBT or some of elements of CBT have also shown promise for helping with apathy (Berardelli et al., 2018; Butterfield et al., 2017)and impulse control difficulties (Jiménez-Murcia et al., 2012; Okai et al., 2013), although more research is needed here. No research was identified which targeted psychosis or more positive psychological constructs such as resilience, self-efficacy and coping.

Motor neurone disease

The review found slightly more studies in MND than HD, but research was still very limited. Levels of anxiety and depression were reduced and quality of life was improved (or deterioration was reduced) by specially adapted versions of mindfulness (Pagnini et al., 2017), individual CBT (Díaz et al., 2016; Van Groenestijn et al.,2015) and an individual psychodynamic approach with hypnosis (Palmieri et al., 2012; Kleinbub et al., 2015) but only one or two studies exist on each of these approaches and only two RCTs (Pagnini et al., 2017; Van Groenestijn et al., 2015). Most interventions also involved carers/family members. All studies had a relatively brief intervention period, most were 8 weeks or less and the one longer study had few people complete it (Van Groenestijn et al., 2015). Furthermore, recruitment was noted to be difficult in both RCTs, due to both health limitations and lack of interest.

One additional study looked at dignity therapy with pwMND and their carers including those who used AAC tools (Aoun et al., 2015). Although changes in quality of life were not significant, the therapy was well-received and this study is notable for enabling those with reduced communication abilities to access therapy.

As a systematic review also concluded (Gould et al., 2015), currently it would be premature to suggest which psychological interventions may help pwMND. Nonetheless, there are areas

of promise to be further investigated. However, consideration will need to be given to the necessary adaptations including length of intervention and accessibility.

Multiple sclerosis

The condition with by far the most research was MS. Depression and low mood was the most frequently targeted difficulty for pwMS. Individual CBT was effective at reducing depression, as largely was telephone and computerised CBT, and group CBT also had mainly positive findings. For some studies the effect was maintained at six months and beyond, including in RCTs (e.g., Ehde et al., 2015; Mohr et al., 2001; Mohr et al., 2005). Mindfulness-based approaches, whether delivered in person or via video calls, also reduced depression levels (e.g. RCTs by Carletto et al., 2017; Cavalera et al., 2018; Grossman et al., 2010; Kolahkaj & Zargar, 2015; Simpson et al., 2017) , although often the effects decreased more long-term. Outcomes were mixed for ACT but it has been little studied (Masjedi-Araani et al., 2018; Nordin & Rorsman, 2012). Approaches which reduced depression in a single RCT included supportive-expression therapy (Mohr et al., 2001) and insight-oriented therapy (Crawford & McIvor, 1985), although the former less so than individual CBT. A self-management intervention showed a trend towards reducing depression (Barlow et al., 2009). Non-RCT studies also looked at positive psychology (Leclaire et al., 2018), a wellness programme (McGuire et al., 2015), a social cognitive treatment (Jongen et al., 2016), DBT (Blair et al., 2007) and various integrative treatments and either significant decreases in depression or decreases at a trend level were observed.

Higher quality anxiety intervention studies (i.e., RCTs) have been mainly group-based. Group based CBT was effective both for anxiety generally (e.g. Pahlavanzadeh et al., 2017; Robati & Shareh, 2018) and OCD (Sayyah et al., 2016), and mindfulness-based groups (e.g. RCTs by Cavalera et al., 2018; Kolahkaj & Zargar, 2015; and Simpson et al., 2017) were also effective

for anxiety, although in both cases it is unknown whether effects were maintained (for 6+ months). Individual CBT studies had less strong designs and also showed some improvement in anxiety and health anxiety. ACT was less well studied; a bibliotherapy self-help intervention found improvements but there was high dropout (Proctor et al., 2018), and a short group ACT intervention had outcomes no different from relaxation (Nordin & Rorsman, 2012). An RCT studying EMDR and relaxation for PTSD found both had positive effects but EMDR was more effective and the effects were maintained at 6 months (Carletto et al., 2016). Other non-RCT group studies with positive findings include a psychoeducational MS wellness programme (McGuire et al., 2015) and a self-efficacy programme (Jongen et al., 2016; effective for RRMS but not PPMS). No changes in anxiety were found for an integrative approach including perceptions of body image (Tesar et al., 2003), an insight-oriented psychotherapy (Crawford and McIvor, 1985), a positive psychotherapy approach (Leclaire et al., 2018) and for positive psychotherapy combined with CBT (Anderson et al., 2017). However, with only one or two studies on each and long-term follow up generally lacking it is harder to draw conclusions for these.

One RCT (Pahlavanzadeh et al., 2017) suggested stress was improved by group CBT interventions. The mindfulness-based interventions were also largely (but not universally) effective in reducing stress at immediate follow up. A psychoeducational MS wellness programme (McGuire et al., 2015) also reduced stress in one study. However, the long-term effects are unclear for all these approaches.

Fatigue has also been well studied. CBT, delivered individually, in person, by telephone and online, has been found to be effective including up to 6 months or more (e.g., Ehde et al., 2018; van Kessel et al., 2008). However, long term follow-up data were not collected for the online programmes and one had a low completion rate, without additional support (van

Kessel et al., 2016). Outcomes from group programmes with CBT elements were mixed, but the groups were quite different in design and one programme had positive effects up to a year (Thomas et al., 2014). Outcomes from mindfulness interventions were largely (but not always) positive (e.g., see RCTs by Grossman et al., 2010; Cavaerla et al, 2018); it is unclear how important specific elements are for reducing fatigue (Bogosian et al., 2015; Spitzer & Pakenham, 2018). Relaxation may also improve fatigue but the long-term effects are not clear; one study suggested CBT may be more effective than relaxation (van Kessel et al., 2008). A social-cognitive wellness programme (Jongen et al., 2016) did not reduce fatigue and a self-management programme involving CBT and positive psychology did (Anderson et al., 2017) but each of these findings is from one non-controlled study.

Regarding sleep, CBT, particularly with sleep specific components, appeared to be a promising intervention from the case studies and one RCT (Abbasi et al., 2016). Another RCT (Cavalera et al., 2018) also suggested mindfulness delivered via video call may be helpful, but benefits were not retained at 6 months. Relaxation also appeared to offer benefits from the one uncontrolled study (Dayaploglu & Tan, 2012) but further research is needed to see if benefits can be maintained long-term.

Some studies used more global assessments of adjustment, although this term was not used consistently by all. CBT studies showed some evidence of improved adjustment, but not universally at one year follow up. One study compared individual and group CBT and found similar results, although the individual sessions were better attended, with a trend towards better outcomes (Das Nair et al., 2016). One study looked specifically at sexual adjustment using a 'mindfulness psychoeducational' programme with non-significant main outcome (Hocaloski et al., 2016).

Two other non-RCT studies looked at psychosocial wellbeing more generally (a half day ACT workshop, Sheppard et al., 2013; and a relationship enhancement programme, Tompkins et al., 2013) and both found positive effects at short-term follow up. When considering quality of life and wellbeing, group CBT findings were also largely positive for improving at least some aspects of quality of life and/or wellbeing at immediate follow up. Mindfulness-based interventions also had largely positive findings at immediate follow up, but more mixed longer-term outcomes. Supportive expression therapy, illness education, a social-cognitive wellness programme, and positive psychology all had one study showing largely positive effects on quality of life (Abolghasemi et al., 2016; Jongen et al., 2016; Leclaire et al., 2018).

Four studies had looked at coping (including one RCT; Foley et al., 1987) and one RCT (Rigby et al., 2008) and one non-RCT had looked at resilience (Pakenham et al., 2018). All generally found positive effects but the approaches were quite different so it is hard to be conclusive about specific interventions, but it is noted that therapeutic approaches can be successful in this regard. Similarly, there were some promising findings from the three studies looking at hope, but mixed findings from the two studies looking at optimism with a variety of approaches utilised. However, high quality RCTs for these outcomes were lacking.

Self-efficacy was improved in one group CBT RCT (Graziano et al., 2014) and in another RCT both by groups focusing on cognitive appraisals, coping and education and those receiving just education and social discussions (Rigby et al., 2008). Outcomes from self-management programmes and a social cognitive wellness programme were also largely positive, although the latter was for people with RRMS and not PPMS (Jongen et al., 2016).

Pain has not been well-studied with only one RCT found which found reductions in pain from a CBT intervention but these were similar to those receiving psychoeducation (Ehde et al., 2015). Effects were sustained up to 12 months. The approaches investigated by the other less

rigorous studies involving elements of CBT, ACT and hypnosis suggest this is an area for further study.

One RCT (Mohr et al., 2005) of telephone CBT versus supportive emotion-focused therapy found greater improvements in positive affect for CBT post-intervention, with benefits retained at one year (though group differences disappeared). Other less rigorous studies on positive and negative affect including CBT, mindfulness and positive psychology had mixed findings. The two studies on self-esteem similarly had mixed findings (Crawford & McIvor, 1985; Robati & Shareh's, 2018).

A study on body image (Tesar et al., 2003) and one on identity and sense of coherence (Graziano et al., 2014) both had non-significant findings. One study on personality and temperament (Crescentini et al., 2018) found MBSR led to some changes, but all these findings would need replication in other studies. No studies have explored apathy specifically, but other studies gave an indication that related constructs of activation and initiation can change as a result of interventions (Ehde et al., 2018; Langenmayr & Schottes, 2000), so given the impact of apathy on pwMS, this area is also worth further study.

Psychological approaches

CBT (including programmes with a large CBT element) and mindfulness were the interventions used in the majority of the studies reviewed, particularly for RCTs, perhaps because they can be manualised. Generally, these were effective, at least in the short term, and (for CBT) whether delivered in person or in a group. ACT, as a newer third wave approach, is just beginning to be researched so the current evidence for interventions using this broad approach is limited, however further trials are currently underway (e.g., for MND,

https://www.ucl.ac.uk/psychiatry/research/mental-health-older-people/past-projects/commend).

Multi-component programmes differed considerably in terms of content and length so were somewhat difficult to compare. They often included psychoeducation and a focus on self-management approaches and some included components such as relaxation, stress management, coping strategies, body image and awareness training, techniques from positive psychology and strategies to improve self-efficacy. They usually had a positive effect on at least one targeted outcome, but not always on all and they have been investigated for HD (A'Campo et al., 2012), PD (e.g., Ghielen et al., 2017; Guo et al., 2009; Macht et al., 2007; Santos et al., 2017) and MS (e.g., Anderson et al., 2017; Barlow et al., 2009; Bilgi et al., 2015; Feicke et al., 2014; Foley et al., 1987; Hemmati et al., 2014; Jongen et al., 2016; Kugler et al., 2000; McGuire et al., 2015; Tesar et al., 2003). For further details on these, see individual chapters.

Other approaches that had been investigated in only one or two studies and for which at least one outcome was improved include an insight-oriented psychotherapy group (Crawford & McIvor, 1985); a 15 month psychotherapy group (Langenmayr & Schottes, 2000), psychotherapy including psychodrama (Sproesser et al., 2010), a psychodynamic hypnosis-based intervention (Kleinbub et al., 2015), self-hypnosis with cognitive restructuring (Jensen et al., 2011), EMDR for PTSD (Carletto et al., 2016), DBT (Blair et al., 2017), positive psychology (LeClaire et al., 2018), supportive expressive therapy (Abolghasemi et al., 2016; Mohr et al., 2001), and a relationship enrichment programmes for couples (Tompkins et al., 2013). However, most of these findings would need replication, including in RCTs, before conclusions could be drawn. Relaxation alone had also been investigated mainly for fatigue (Dayapoğlu & Tan, 2012; Sgoifo et al., 2017; van Kessel et al., 2008; Vazirinejad et al., 2016). CBT was more

effective for fatigue in one study (van Kessel et al., 2008) and CBT was more effective than supportive expressive therapy for depression in another (Mohr et al., 2001). For further details see separate chapters.

Manualised approaches will not always be appropriate and a formulation may suggest the need for a bespoke intervention. While not necessarily demonstrating changes on outcome measures, the case studies and series included here can give an indication of more individualised approaches. For example, EMDR was used with an individual with PD and dementia and trauma (Ahmed et al 2018), behavioural relaxation training and imagery reduced anxiety for a pwPD so they could have surgery (Lundervold et al., 2008), behavioural relaxation training helped a pwPD with social anxiety and dyskinesias (Lundervold et al., 2013), self-focused exposure therapy was used to help a pwPD and social anxiety (Heinrichs et al., 2001), CBT reduced injection anxiety in a pwMS (Cox et al., 2004) and reduced anxiety and depression in someone with HD (Silver, 2003), sensory modulation and behaviour support reduced aggression in a pwHD (Fisher & Brown, 2017), hypnosis and CBT reduced anxiety for a pwMS (Slatter, 2016) and hypnotic imagery and posthypnotic suggestion helped with pain for a pwMS (Dane et al., 1996). Furthermore, a case series of CBT showed reduced health anxiety for some people with MS (Carrigan et al., 2018) and a further case series looked at remotivation therapy in HD (Sullivan et al., 2001).

Impact of disease severity

Given the nature of most of the interventions reported, they are likely to have been with individuals at early disease stages and much less is available about approaches with people with more cognitive and/or physical impairments. While guidance for working with people with dementia was not the focus here (and is available elsewhere; e.g., BPS, 2018), it is

possible some individuals with a mild to moderate degree of impairment could still benefit from approaches covered here. The MS studies often had a majority of participants with RRMS, with a few people with PPMS or SPMS, and the results were often stated for the group as a whole. One study which did report the results separately found improvements for RRMS but not for PPMS (Jongen et al., 2016) suggesting that further adaptations may be needed for this group.

Adaptations that were mentioned in CBT studies included shorter sessions, more repetition, and simplified language and metaphors. Sometimes a greater number of sessions were needed, e.g., 11-20 sessions for depression for people with MS, but equally interventions for MND tended to be shorter, given the often-rapid deterioration for pwMND. Adaptions for mindfulness were similar and in addition certain exercises involving motor or particular sensory components were omitted or reduced and meditation practices were shortened. A pre-course orientation session might be helpful and booster sessions after the end of the course may also be required (Simpson et al., 2019).

Studies which are notable for their inclusion of people with more severe difficulties include Aoun et al. (2015) which had home visits and enabled pwMND using AAC to take part, and Askey-Jones et al. (2013) who studied CBT outcomes for pwMS in clinical practice and who also provided home visits flexibly where necessary to increase accessibility. The case study of CBT with an individual with advanced PD (Richardson & Marshall, 2015) indicated how delivering CBT in a nursing home was possible with adaptations that included involving staff, a focus on behavioural activation, shorter sessions, simplified language and no writing by the client. The case study of Fisher and Brown (2015) with someone with advanced HD used sensory modulation and behaviour support, as well as work with staff to improve aggression.

While the focus in this guidance has been on the individuals with the condition, several of the studies also included family members and carers in the interventions, particularly for MND, but also for the other conditions. This may be another way of increasing accessibility and enabling effects of therapy to persist between and after sessions. Sometimes people want partners involved but equally sometimes want the freedom to speak of difficulties alone (e.g., Weeks et al., 2019). Flexibility and transparent communication around this issue is clearly key.

Other adaptations to enhance accessibility might include considering the time of day; for example older people might prefer the middle of the day, but younger people of working age with working age partners may only be able to access groups outside work.

Indeed, people may need different interventions at different stages of the disease course and it is likely that people will need additional support as the disease progresses. The Neurological Alliance consensus statement for mental health (The Neurological Alliance, 2019a) stipulates such support should take into account both the neurological condition and mental health needs and be tailored to individuals' specific requirements (e.g., in terms of communication and cognitive abilities).

Technology

The use of technology is becoming more widespread. Telephone CBT, accessing mindfulness groups via video calling and automated online CBT, have all been trialled. As well as potentially reducing costs, this can also increase access for some participants. However, it should not be seen as a panacea as the internet is not available or suitable for all. Furthermore, some people with MS found accessing computer CBT too difficult due to cognitive difficulties and fatigue (e.g., Hind et al., 2010). The studies also encountered some technological problems due to software glitches or poor internet connection which could detract from the intervention (e.g.,

Cavalera et al., 2018; Moss-Morris et al., 2012; van Kessel et al., 2016). One purely automated online CBT intervention for MS had very poor completion rates which suggest that this approach may not appropriate without some additional support (either telephone or email) to enable people to complete the intervention (van Kessel et al., 2016). Another trial of computerised CBTi for pwPD also had poor completion rates (Patel et al., 2017).

Future research

Given the paucity of research for pwHD, further research for this group is urgently needed. The positive outcomes for other conditions in this guidance suggest it is worth pursuing. However, given the rarity of HD, groups may be difficult and therapy may need to be delivered via online methods or individually. Further education of health care staff that psychological interventions are possible may also be needed as it is often viewed as a purely biological condition with pharmacological interventions the only option.

For pwPD, limited research exists in all areas but particularly in the areas of apathy, impulse control and psychosis. However, even for more common difficulties such as depression and anxiety, only a limited number of approaches have been well-studied in RCTs.

For pwMND, research can build on the current promising findings. A recent study (Weeks et al., 2019) suggested issues of identity, loss, stigma, embarrassment, frustration, denial and uncertainty were important to be addressed and therefore interventions may need to think beyond aims such as reducing anxiety or depression. However, given some previous studies struggled with recruitment levels, attention will need to be paid to accessibility and suitability of the intervention.

For MS, pain, apathy and sleep have little research or none compared to other areas. In addition, more is needed for PPMS and SPMS as it may be that further adaptations are needed

for this group. Certainly, research should consider reporting outcomes for these groups so that knowledge of what does (and does not) help can be increased.

While a few studies exist (A'Campo et al., 2012; J. K. Anderson et al., 2017; Feicke et al., 2014; Leclaire et al., 2018; Sinclair & Scroggie, 2005; Tesar et al., 2003), more approaches which focus on positives such as improving coping, resilience, optimism and hope would also be welcomed. Furthermore, despite its frequent report, interventions to support individuals with a range of anxiety-based problems are still less evident than those for low mood. The lack of research into positive outcomes and experiences (Barak & Achiron, 2009) into neurological conditions generally has been noted and the emphasis on only targeting negative states does not sit well with attempts to improve quality of life and enhance psychological well-being. With the exception of the described research in MS, little work on resilience building or other preventative work to help reduce the development of psychological distress has been conducted. While such research is more problematic to evidence as effective, building effective coping and other life skills is crucial when managing a long-term condition.

RCTs need to evidence longer term outcomes (e.g., up to a year) for at least early stage HD, PD and MS. Given the rapid progression of MND, it is acknowledged this may be less appropriate for some individuals. Some interventions which had longer follow ups noted reduced effects over time, so researchers could also investigate ways to help the gains be maintained (e.g., booster sessions). It is important both to create an evidence base which uses longitudinal research to encompass fully the fluctuations inherent in these conditions and to conduct research for people at more of the discrete and identifiable stages (i.e., in relation to individuals with younger onset Parkinson's or pre-manifest HD).

In general, more innovative ways (such as those which do not just focus on the individual as the target of an intervention) may be needed to help people with more severe disease and a

greater range of therapies could be investigated. As the Neurological Alliance note, a range of therapies are needed to be able to target individual needs and the complexities of working with people with neurological conditions therefore more research is needed (The Neurological Alliance, 2017).

Economics

Assessing the economic benefits of the various interventions included in this guidance has not been a priority currently. Although the economic benefits of psychological therapies have been demonstrated (Layard et al., 2007), this has been largely related to working adults and the effects of therapy on reducing absence from work or inability to work. We found only a few studies (e.g., Bogosian et al., 2015; Humphreys et al., 2013; Moss-Morris et al., 2012; Thomas et al., 2013) as part of this review which included an economic analysis. While clearly further research in this area is important in demonstrating cost-effectiveness, proper consideration needs to be paid to the other costs likely to be reduced through effective engagement with psychological therapies. Given the wide-ranging effects of poorer psychological functioning on health outcomes, indices such as number of emergency admissions to hospital, medication compliance, etc., could be argued to be relevant. No specific data exists for neurological conditions, but recent figures suggests that for people with long term conditions the cost of care increases by an average of 45% following the development of mental health difficulties (NHS England, 2016). By treating a person's mental health concerns in tandem with their physical health, around £1760 per person in annual expenditure on physical health care costs may be saved (NHS England & NHS Improvement, 2018).

Service provision

The Neurological Alliance, working in partnership with the BPS's Division of Neuropsychology and other patient organisations, has explored the mental health, emotional and cognitive needs of people with neurological conditions living in England, including the conditions detailed in this guidance (The Neurological Alliance, 2017). In particular, the report highlights the complex interplay between neurological conditions and mental health and why people with neurological conditions may have specific needs in regards to improving mental health.

However, the Neurological Alliance's 2019 national neurology patient experience survey in England suggested that many people with neurological conditions are not receiving help with their mental health; 30% of those who wanted it had not been referred or signposted to mental health support and 40% said their needs were not being met at all regarding mental health (The Neurological Alliance, 2019b). Similarly, the All Party Parliamentary Group (APPG) for Parkinson's highlighted the difficulties for pwPD in accessing psychological help in all four nations (APPG for Parkinson's, 2018) and the 2016 My MS My Needs survey suggested while 23% of pwMS had accessed support for mood and emotional difficulties, 21% said they wanted more support (Redfern-Tofts et al., 2016)

The fact many individuals are lacking support is perhaps not surprising as the Neurological Alliance (2017) report concluded that current services have "disjointed pathways, poorly coordinated care and variation across the country" (p.6). Even signposting to self-management or other information, e.g., that available from third sector organisations, can be poor. The report also found that access to mental health services can be denied when difficulties are seen to have an organic origin, or even when accessed, the staff do not have the relevant training to meet the person's needs. This review has not assessed the importance staff training – partly because of the lack of research in this area – but its importance is crucial.

Training professionals working within the health and social care sector to develop the skills to signpost to relevant services, to understand the value of psychological approaches and, where appropriate, to offer psychological support or therapy has to be a priority. A recent survey (Barcroft et al., 2016)of psychologists (mostly clinical and neuropsychologists; *n* = 149) showed that around a third reported no specific teaching on individuals with motor NDDs as part of their training and a similar proportion reported having no related CPD in the last 12 months. Given that it might be expected, due to the extensive training of these professionals, that motor NDD teaching would be appropriately featured, it is disappointing to see that even within this profession, relevant training is not being provided.

To our knowledge, a detailed survey across neurological conditions similar to the one conducted by the Neurological Alliance in England (2017) has not been conducted in Scotland, Wales and Northern Ireland. However, the Neurological Conditions Delivery Plan in Wales suggested that the coordination of care between services and agencies could "appear fragmented and confusing" both for staff and for those with neurological conditions (NHS Wales, 2017, p. 6). As noted in the BPS response document (BPS, 2019), the Neurological Conditions Draft Action Plan 2019 for Scotland (Scottish Government, 2018) contains very little mention of psychological functioning and mental health, suggesting it is not a priority.

Furthermore, it may be a recommendation in policy documents that access to psychology or neuropsychology is provided (e.g., Healthcare Improvement Scotland, 2019; NHS Wales, 2017) and that there is parity in esteem between mental and physical health (e.g., Northern Ireland Department of Health, 2019a). However, in practice access to specialists, including psychologists and neuropsychologists, can be patchy or non-existent (e.g., NHS Wales, 2017; Northern Ireland Department of Health Neurology Review Team, 2019; The Neurological Alliance, 2019b). It is also important that guidance from bodies such as NICE detail and refer

to the need for support for mental health specifically as part of these conditions, as opposed to simply signposting to mainstream adult services guidelines.

NHS England's RightCare progressive neurological conditions toolkit (covering PD, MND and MS) suggests one of the key national challenges is lack of availability of appropriate psychosocial support (NHS RightCare, 2019). It suggests that the available options of mental health support should be made clear to people with neurological conditions and their families and "support from specialist neuropsychiatry or neuropsychology services should be made available if required".

The Neurological Alliance have suggested that within the neuroscience pathway there should be "psychological triage" to decide whose needs may be met by general mental health services and who may need a more specialist intervention (The Neurological Alliance, 2017, 2018). Service models would need to be flexible to allow for different modes of delivery to respond to cognitive and communication needs (e.g., groups may not always be appropriate and accessibility would need to be considered).

In addition, better care pathways are needed between mental health and neurology, and mental health services will need input from psychology and psychiatry professionals with appropriate expertise. More training and support for mental health workers, such as those in IAPT, so they can work with people with neurological conditions has also been suggested (The Neurological Alliance, 2018).

This guidance has suggested that, firstly, more research is needed across all conditions but in particular for individuals with HD, PD and MND. Research is crucial in helping professionals determine which psychological approaches might be appropriate for an individual within the context of a psychological formulation. However, the provision of psychological support can clearly not be delayed until more evidence is published and so, in the meantime, professionals

must work with the limited evidence currently available and the more generic guidance available. Informal networks of interested practitioners (e.g., the Mental Health Hub recently set up by Parkinson's UK) are essential to form a multi-disciplinary supportive and educational environment to share current good practice. Secondly, across all conditions, current access to psychological support is not acceptable. While this document, in this respect, is simply echoing repeated expressions of this same message from multiple other organisations, it is vital that the need to provide evidence is also linked to the need to improve and develop services. Evidence loses its potential without appropriate services being able to support its conclusions. We therefore hope that this guidance will both encourage the provision of high-quality evidence and support the development of effective, timely and accessible psychological support.

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APPENDIX A

LITERATURE REVIEW METHODS AND PROCEDURE

Methods

Methodological approach

For the purpose of this guidance, a scoping systematic review was adopted, following the guidance outlined by the Joanna Briggs Institute (Peters et al., 2015). This approach was chosen due to the heterogeneous nature of the targeted research (i.e., quantitative, qualitative, guidance) and since it allowed the use of a systematic and replicable search strategy without specifying a narrowly defined research question, as usually required by systematic reviews (Arksey & O'Malley, 2005; Mays et al., 2001). The paucity of research for some conditions and lack of comprehensive reviews on psychological factors and interventions with people with the four conditions of interest meant a narrow search focus would not enable the aims of the search to be met (Peters et al., 2015; Pham et al., 2014).

Research questions

The literature review was guided by the following research questions:

1. What are the psychological outcomes investigated in people with HD, PD, MND and MS?
2. What psychological interventions have been adopted with people with HD, PD, MND and MS?

Inclusion and exclusion criteria

To be included in the present review, studies and guidelines had to present the following characteristics:

- Relating to people with PD, HD, MS, or MND.
- Involving participants aged 18 or above.

- Describing the delivery of any form of psychological intervention aimed at improving psychological well-being.

Studies presenting any of the following characteristics were excluded:

- Not published in full in the English language.
- Involving or relating mainly to animals.
- Involving or relating mainly to cognitive functioning.
- Discussions of multi-disciplinary (MDT) care unless there was a substantial defined non-pharmacological contribution by a psychologist/mental health practitioner.
- Self-management/multi-component programmes without a significant psychological component and/or psychological design.
- Self-management programmes focused on some aspect of physical health.
- Interventions where the use of psychological techniques was mainly to improve physical health (e.g., motivational interviewing to increase exercise).
- Forms of therapy focused on the creative arts (e.g., art therapy, drama therapy, music therapy).
- Literature focused on the genetic testing for HD.
- Neurofeedback and biofeedback.

Study designs and methods

Quantitative, qualitative and mixed methods research studies were included in the review. Systematic reviews, reviews, commentaries, editorials and letters were excluded.

Context

Studies from all healthcare settings were considered eligible. No geographical limits were applied to the database searches for published literature.

Quality assessment

Since a formal quality appraisal is not a typical component of scoping reviews (Peters et al., 2015; Pham et al., 2014), no quality assessment was performed on the identified studies.

Procedure

Search strategies

A comprehensive search was performed in the following databases, using a combination of free text terms:

- Academic Search Ultimate
- CINAHL
- Cochrane Library
- PsycINFO
- PubMed

Hand-searches were also carried out in reference lists of included studies and key reviews in order to identify further relevant citations. Table 1 shows the logic grid for the research strategy. Table 2 provides an overview of the adopted search terms and identified items for each database.

Study selection

Results from searches of electronic databases were imported into a reference management software, where duplicate citations were removed. Studies and guidelines were selected using the eligibility criteria described above. In the first phase, all titles were screened by one reviewer, and those that clearly did not meet the inclusion criteria were excluded. In the second stage, all abstracts and full text articles were screened for eligibility by one reviewer and confirmed by a second reviewer. Figure 1 illustrates the PRISMA flow diagram of the study selection process.

Data extraction

Selected data items were coded and extracted into an Excel sheet. Data were extracted by a single reviewer and double-checked by a second reviewer to ensure accuracy. The data extraction tables can be viewed and downloaded here: [LINK].

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APPENDIX B

TABLES AND FIGURES

Table 1: Logic grid for research strategy

Population	Interventions	
Huntington* disease	Acceptance and commitment therapy	Motivational interviewing
Motor neuron* disease	Behavio* therapy	Narrative therapy
Amyotrophic lateral sclerosis	Cognitive analytic therapy	Person cent* therapy
Multiple sclerosis	Cognitive behavio* therapy	Psychoanal*
Parkinson* disease	Cognitive therapy	Psychodynamic therapy
	Compassion* focused therapy	Psychoeducati*
	Counsel*	Psychological intervention
	Couple* therapy	Psychotherap*
	Dialectical behavioral therapy	Rational emotive behavio* therapy
	Emotion focused therapy	Schema therapy
	Emotive behavio* therapy	Self-management
	Eye movement desensiti* and reprocessing	Solution focused therapy
	Family therapy	Systemic therapy
	Gestalt therapy	
	Group* therapy	
	Integrative therapy	
	Interpersonal therapy	
	Meditat*	
	Metacognitive therapy	
	Mindfulness	
	Mindfulness-based cognitive therapy	
	Mindfulness-based stress reduction	

Note: * = truncation searching.

Table 2: Overview of adopted search terms and identified items.

Condition	Search Terms	Database	Items
HD	(Huntington* disease AND Acceptance and commitment therapy) OR (Huntington* disease AND Behavio* therapy) OR (Huntington* disease AND Cognitive analytic therapy) OR (Huntington* disease AND Cognitive behavio* therapy) OR (Huntington* disease AND Cognitive therapy) OR (Huntington* disease AND Compassion* focused therapy) OR (Huntington* disease AND Counsel*) OR (Huntington* disease AND Couple* therapy) OR (Huntington* disease AND Dialectical behavioral therapy) OR (Huntington* disease AND Emotion focused therapy) OR (Huntington* disease AND Emotive behavio* therapy) OR (Huntington* disease AND Eye movement desensiti* and reprocessing) OR (Huntington* disease AND Family therapy) OR (Huntington* disease AND Gestalt therapy) OR (Huntington* disease AND Group* therapy) OR (Huntington* disease AND Integrative therapy) OR (Huntington* disease AND Interpersonal therapy) OR (Huntington* disease AND Meditat*) OR (Huntington* disease AND Metacognitive therapy) OR (Huntington* disease AND Mindfulness) OR (Huntington* disease AND Mindfulness-based cognitive therapy) OR (Huntington* disease AND Mindfulness-based stress reduction) OR (Huntington* disease AND Motivational interviewing) OR (Huntington* disease AND Narrative therapy) OR (Huntington* disease AND Person cent* therapy) OR (Huntington* disease AND Psychoanal*) OR (Huntington* disease AND Psychodynamic therapy) OR (Huntington* disease AND Psychoeducati*) OR (Huntington* disease AND Psychological intervention) OR (Huntington* disease AND Psychotherap*) OR (Huntington* disease AND Rational emotive behavio* therapy) OR (Huntington* disease AND Schema therapy) OR (Huntington* disease AND Self-management) OR (Huntington* disease AND Solution focused therapy) OR (Huntington* disease AND Systemic therapy)	Medline Complete	751
		PsycINFO	331
		CINHAL Complete	126
		Academic Search Ultimate	301
		Cochrane Reviews	3
MND	(Motor neuron* disease AND Acceptance and commitment therapy) OR (Motor neuron* disease AND Behavio* therapy) OR (Motor neuron* disease AND Cognitive analytic therapy) OR (Motor neuron* disease AND Cognitive behavio* therapy) OR (Motor neuron* disease AND Cognitive therapy) OR (Motor neuron* disease AND Compassion* focused therapy) OR (Motor neuron* disease AND Counsel*) OR (Motor neuron* disease AND Couple* therapy) OR (Motor neuron* disease AND Dialectical behavioral therapy) OR (Motor neuron* disease AND Emotion focused therapy) OR (Motor neuron* disease AND Emotive behavio* therapy) OR (Motor neuron* disease AND Eye movement desensiti* and reprocessing) OR (Motor neuron* disease AND Family therapy) OR (Motor neuron* disease AND Gestalt therapy) OR (Motor neuron* disease AND Group* therapy) OR (Motor neuron* disease AND Integrative therapy) OR (Motor neuron* disease AND Interpersonal therapy) OR (Motor neuron*	Medline Complete	107
		PsycINFO	64
		CINHAL Complete	38
		Academic Search Ultimate	146

	disease AND Meditat*) OR (Motor neuron* disease AND Metacognitive therapy) OR (Motor neuron* disease AND Mindfulness) OR (Motor neuron* disease AND Mindfulness-based cognitive therapy) OR (Motor neuron* disease AND Mindfulness-based stress reduction) OR (Motor neuron* disease AND Motivational interviewing) OR (Motor neuron* disease AND Narrative therapy) OR (Motor neuron* disease AND Person cent* therapy) OR (Motor neuron* disease AND Psychoanal*) OR (Motor neuron* disease AND Psychodynamic therapy) OR (Motor neuron* disease AND Psychoeducati*) OR (Motor neuron* disease AND Psychological intervention) OR (Motor neuron* disease AND Psychotherap*) OR (Motor neuron* disease AND Rational emotive behavio* therapy) OR (Motor neuron* disease AND Schema therapy) OR (Motor neuron* disease AND Self-management) OR (Motor neuron* disease AND Solution focused therapy) OR (Motor neuron* disease AND Systemic therapy)	Cochraine Reviews	31
ALS	(Amyotrophic lateral sclerosis AND Acceptance and commitment therapy) OR (Amyotrophic lateral sclerosis AND Behavio* therapy) OR (Amyotrophic lateral sclerosis AND Cognitive analytic therapy) OR (Amyotrophic lateral sclerosis AND Cognitive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Cognitive therapy) OR (Amyotrophic lateral sclerosis AND Compassion* focused therapy) OR (Amyotrophic lateral sclerosis AND Counsel*) OR (Amyotrophic lateral sclerosis AND Couple* therapy) OR (Amyotrophic lateral sclerosis AND Dialectical behavioral therapy) OR (Amyotrophic lateral sclerosis AND Emotion focused therapy) OR (Amyotrophic lateral sclerosis AND Emotive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Eye movement desensiti* and reprocessing) OR (Amyotrophic lateral sclerosis AND Family therapy) OR (Amyotrophic lateral sclerosis AND Gestalt therapy) OR (Amyotrophic lateral sclerosis AND Group* therapy) OR (Amyotrophic lateral sclerosis AND Integrative therapy) OR (Amyotrophic lateral sclerosis AND Interpersonal therapy) OR (Amyotrophic lateral sclerosis AND Meditat*) OR (Amyotrophic lateral sclerosis AND Metacognitive therapy) OR (Amyotrophic lateral sclerosis AND Mindfulness) OR (Amyotrophic lateral sclerosis AND Mindfulness-based cognitive therapy) OR (Amyotrophic lateral sclerosis AND Mindfulness-based stress reduction) OR (Amyotrophic lateral sclerosis AND Motivational interviewing) OR (Amyotrophic lateral sclerosis AND Narrative therapy) OR (Amyotrophic lateral sclerosis AND Person cent* therapy) OR (Amyotrophic lateral sclerosis AND Psychoanal*) OR (Amyotrophic lateral sclerosis AND Psychodynamic therapy) OR (Amyotrophic lateral sclerosis AND Psychoeducati*) OR (Amyotrophic lateral sclerosis AND Psychological intervention) OR (Amyotrophic lateral sclerosis AND Psychotherap*) OR (Amyotrophic lateral sclerosis AND Rational emotive behavio* therapy) OR (Amyotrophic lateral sclerosis AND Schema therapy) OR (Amyotrophic lateral sclerosis AND Self-management) OR (Amyotrophic lateral sclerosis AND Solution focused therapy) OR (Amyotrophic lateral sclerosis AND Systemic therapy)	Medline Complete	253
		PsycINFO	154
		CINHAL Complete	73
		Academic Search Ultimate	185
		Cochraine Reviews	23
MS	(Multiple sclerosis AND Acceptance and commitment therapy) OR (Multiple sclerosis AND Behavio* therapy) OR (Multiple sclerosis AND Cognitive analytic therapy) OR (Multiple sclerosis AND	Medline Complete	1383

	Cognitive behavio* therapy) OR (Multiple sclerosis AND Cognitive therapy) OR (Multiple sclerosis AND Compassion* focused therapy) OR (Multiple sclerosis AND Counsel*) OR (Multiple sclerosis AND Couple* therapy) OR (Multiple sclerosis AND Dialectical behavioral therapy) OR (Multiple sclerosis AND Emotion focused therapy) OR (Multiple sclerosis AND Emotive behavio* therapy) OR (Multiple sclerosis AND Eye movement desensiti* and reprocessing) OR (Multiple sclerosis AND Family therapy) OR (Multiple sclerosis AND Gestalt therapy) OR (Multiple sclerosis AND Group* therapy) OR (Multiple sclerosis AND Integrative therapy) OR (Multiple sclerosis AND Interpersonal therapy) OR (Multiple sclerosis AND Meditat*) OR (Multiple sclerosis AND Metacognitive therapy) OR (Multiple sclerosis AND Mindfulness) OR (Multiple sclerosis AND Mindfulness-based cognitive therapy) OR (Multiple sclerosis AND Mindfulness-based stress reduction) OR (Multiple sclerosis AND Motivational interviewing) OR (Multiple sclerosis AND Narrative therapy) OR (Multiple sclerosis AND Person cent* therapy) OR (Multiple sclerosis AND Psychoanal*) OR (Multiple sclerosis AND Psychodynamic therapy) OR (Multiple sclerosis AND Psychoeducati*) OR (Multiple sclerosis AND Psychological intervention) OR (Multiple sclerosis AND Psychotherap*) OR (Multiple sclerosis AND Rational emotive behavio* therapy) OR (Multiple sclerosis AND Schema therapy) OR (Multiple sclerosis AND Self-management) OR (Multiple sclerosis AND Solution focused therapy) OR (Multiple sclerosis AND Systemic therapy)	PsycINFO	865
		CINHAL Complete	664
		Academic Search Ultimate	902
		Cochraine Reviews	73
PD	(Parkinson* disease AND Acceptance and commitment therapy) OR (Parkinson* disease AND Behavio* therapy) OR (Parkinson* disease AND Cognitive analytic therapy) OR (Parkinson* disease AND Cognitive behavio* therapy) OR (Parkinson* disease AND Cognitive therapy) OR (Parkinson* disease AND Compassion* focused therapy) OR (Parkinson* disease AND Counsel*) OR (Parkinson* disease AND Couple* therapy) OR (Parkinson* disease AND Dialectical behavioral therapy) OR (Parkinson* disease AND Emotion focused therapy) OR (Parkinson* disease AND Emotive behavio* therapy) OR (Parkinson* disease AND Eye movement desensiti* and reprocessing) OR (Parkinson* disease AND Family therapy) OR (Parkinson* disease AND Gestalt therapy) OR (Parkinson* disease AND Group* therapy) OR (Parkinson* disease AND Integrative therapy) OR (Parkinson* disease AND Interpersonal therapy) OR (Parkinson* disease AND Meditat*) OR (Parkinson* disease AND Metacognitive therapy) OR (Parkinson* disease AND Mindfulness) OR (Parkinson* disease AND Mindfulness-based cognitive therapy) OR (Parkinson* disease AND Mindfulness-based stress reduction) OR (Parkinson* disease AND Motivational interviewing) OR (Parkinson* disease AND Narrative therapy) OR (Parkinson* disease AND Person cent* therapy) OR (Parkinson* disease AND Psychoanal*) OR (Parkinson* disease AND Psychodynamic therapy) OR (Parkinson* disease AND Psychoeducati*) OR (Parkinson* disease AND Psychological intervention) OR (Parkinson* disease AND Psychotherap*) OR (Parkinson* disease AND Rational emotive behavio* therapy) OR (Parkinson* disease AND Schema therapy) OR (Parkinson* disease AND Self-management) OR (Parkinson* disease AND Solution focused therapy) OR (Parkinson* disease AND Systemic therapy)	Medline Complete	1460
		PsycINFO	940
		CINHAL Complete	525
		Academic Search Ultimate	1010
		Cochraine Reviews	51

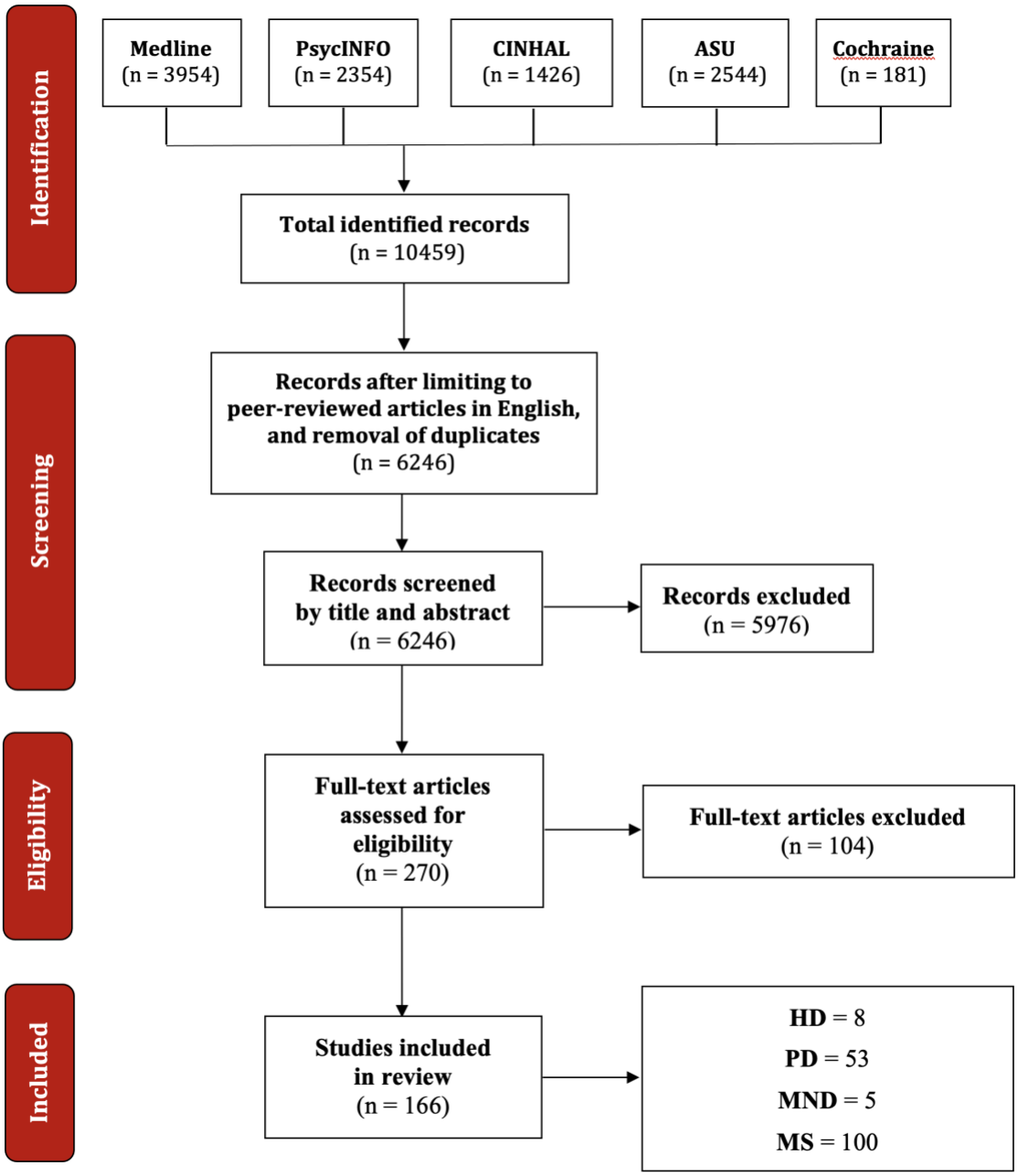

Figure 1. PRISMA flow diagram of the study selection process.

APPENDIX C

GLOSSARY OF THERAPIES

Acceptance and commitment therapy (ACT)

ACT aims to improve individuals' acceptance of distressing thoughts, beliefs, sensations and emotions, contending that this will generate behavioural change and consequently improved quality of life. There is emphasis on moving towards key goals and acting upon values which are most important to the person, designing behavioural changes which direct one towards living these values.

Key references

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2012). Acceptance and commitment therapy: The process and practice of mindful change (2nd ed.). New York: Guilford Press.

Behaviour support modification

Positive behaviour support entails identification of triggers for problematic behaviours, allowing for development of guidelines to change the environment and consequently reduce agitation and distress.

Key references

Dunlap, G., Carr, E. G., Horner, R. H., Zarrcone, J., & Schwartz, I. (2008). Positive behavior support and applied behavior analysis: A familial alliance. *Behavior Modification*, *32*, 682-698. https://doi.org/10.1177%2F0145445508317132

Cognitive behavioural therapy (CBT)

CBT holds that emotional distress and behavioural difficulties arise from "maladaptive" or unhelpful cognitions, which comprise general beliefs about the world, the self and the future. The therapy is

predicated on the assumption that changing these cognitions through therapeutic interventions will reduce distress and problematic behaviours.

Key references

Beck, A. T. (1970). Cognitive therapy: Nature and relation to behavior therapy. *Behavior Therapy*, *1*, 184-200.

Beck, J.S. (2011). *Cognitive Behavior Therapy, Second Edition: Basics and Beyond.* The Guilford Press: New York.

Hofmann, S. G., Asnaani, A., Vonk, I. J. J., Sawyer, A. T. & Fang, A. (2012). The efficacy of cognitive behavioural therapy: A review of meta-analyses. *Cognitive Therapy and Research*, *36*(5), 427-440. https://doi.org/10.1007/s10608-012-9476-1

Dialectical behaviour therapy (DBT)

DBT was developed from CBT; while it retains the focus on changing unhelpful cognitions and behaviours to improve well-being, there is an additional importance placed upon self-acceptance, validation of experiences and emotional regulation/coping. While usually associated with borderline personality disorder, DBT is increasingly used in other client groups and the emphasis on acceptance and emotional management may be particularly helpful for individuals adjusting to lifelong, or life-limiting, neurological diagnoses.

Key references

Dimeff, L. A., & Koerner, K. (2007). *Dialectical behavior therapy in clinical practice: Applications across disorders and settings.* New York: Guilford Press.

Linehan, M. M. (2014). *DBT skills training manual* (2nd ed.). New York: Guilford Press.

Dignity therapy

Dignity therapy is a brief approach based on an empirically-validated model of dignity in terminally ill people. The participants are invited to discuss the issues that matter most of them, or that they most want to be remembered about their life. Sessions are transcribed and returned to the individuals, to be bequeathed to someone important to them.

Key references

Aoun, S. M., Chochinov, H. M., & Kristjanson, L. J. (2015). Dignity therapy for people with motor neuron disease and their family caregivers: a feasibility study. *Journal of Pallative Medicine*, *18*(1), 31–37. https://doi.org/10.1089/jpm.2014.0213

Chochinov, H. M. (2002). Dignity-conserving care – a new model for palliative care: Helping the patient feel valued. *Journal of the American Medical Association*, *287*(17), 2253-2260. https://doi.org/10.1001/jama.287.17.2253

Martinez, M., Arantzamendi, M., Belar, A., Carrasco J. M., Carvajal, A., Rullán, M., & Centeno, C. (2017). 'Dignity therapy', a promising intervention in palliative care: A comprehensice systematic literature review. *Palliative Medicine*, *31*(6), 492-509. https://doi.org/10.1177/0269216316665562

Emotion-focused therapy

Emotion-focused therapy centres around the development of emotional intelligence and secure relationships, examining the goals and values of key relationships for the individual and improving emotional skills. The therapy has roots in attachment theory, and it is argued that pain and disruption

within close relationships is an expression of a need for attachment which, when fulfilled, will result in improved well-being and closer relationships.

Key references

Greenberg, L. S. (2004). Emotion-focused therapy. *Clinical Psychology and Psychotherapy*, *11*, 3-16. https://doi.org/10.1002/cpp.388

Eye movement desensitisation and reprocessing (EMDR)

EMDR focuses on reprocessing of traumatic memories, including images, emotional and physical responses and changes in self-representation which are associated with the memory. The aim is to support the brain to process trauma, helping individuals to develop more positive self-representation, improve well-being and move forward with their lives.

Key references

Shapiro, F. (2017). Eye movement desensitization and reprocessing (EMDR) therapy: Basic principles, protocols, and procedures (3rd ed.). New York: Guilford Press.

Mindfulness-based approaches

Mindfulness-based approaches focus on bringing the attention to the present moment and accepting feelings, sensations and emotions non-judgementally, including the experience of illness. Such approaches developed for neurological conditions may emphasise acceptance of discomfort and physical changes, focusing on relaxation and appreciation of the abilities and resources which remain. Approaches may include elements of cognitive therapy (MBCT), or may focus on stress reduction (MBSR).

Key references

Crane, R. (2017). Mindfulness-based cognitive therapy. London: Routledge.

Kabat-Zinn, J. (2006). Mindfulness-Based Interventions in Context: Past, Present, and Future. *Clinical Psychology: Science and Practice*, *10*(2), 144–156. https://doi.org/10.1093/clipsy.bpg016

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2013). *Mindfulness-based cognitive therapy for depression* (2nd ed.). New York: New York: Guilford Press.

Psychoeducation

Psychoeducation focuses on developing individuals' understanding about illness and themselves in relation to their condition by provision of information and use of exercises. The aim is to empower the individual to manage their condition and their own reactions to it more successfully and consequently improve their well-being. Programmes may include elements of CBT (e.g., cognitive restructuring), behavioural activation, development of stress coping strategies, social skills training, role play, and relaxation skills development. Content is tailored to the specific condition (examples from studies of HD, MS and PD are in the references below).

Key references

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Relaxation training (incl. progressive muscle relaxation)

Relaxation-based interventions focus on relieving muscle tension, on the hypothesis that muscular tension is a physiological response to anxiety, and that therefore relaxing the muscles will reduce anxiety. Techniques may involve progressive attention to muscle groups, tensing and releasing in turn while focusing on the sensation of release following tension, and this may be supported by relaxing music or guided narratives to assist the exercises.

Key references

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Remotivation therapy

Remotivation therapy is a five-step, structured technique which focuses on increasing quality of life by improving self-awareness, and restoring/maintaining social and mental functioning. It focuses on motivating and engaging individuals to seek fulfilment, focusing on abilities rather than disabilities, and was originally intended for use with people who had become non-verbal and withdrawn. It has

since been demonstrated effective in other neurological conditions, and was trialled in HD in Sullivan et al.'s (2001) study.

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APPENDIX D

GLOSSARY OF STUDIES

A decision was taken not to exclude certain types of studies, largely because of the dearth of evidence in many conditions. We have also not included a quality checklist on the basis that the designs are so different one checklist would not be appropriate and we did not want to rate certain studies as low (compared to more controlled studies) when their aims articulated a more modest contribution to the evidence base. However, we have given more emphasis in the condition narratives to studies where the designs have been more rigorous. Such designs include randomised controlled trials and other designs where some attempt at control has been made. For more information on traditional hierarchies used to evaluate research, see Evans (2003).

Case-control

Retrospective analysis of past exposures in a group of participants plus one (or more) acting as controls. There is usually a known condition, but the differences in exposure are unknown. The study begins after the onset of the condition.

Case series

Description of common characteristics in a number of cases. There are no control group and no statistical analysis. It represents a very low level of evidence, but can be useful to generate new hypotheses.

Case study

Description of a single occurrence/case of a condition. It often consists only of a clinical narrative. It represents the lowest level of scientific evidence, but it can be useful as first illustration of a new condition.

Cohort study

Investigation of a group of people sharing common characteristics ('cohort'). It explores the links between known exposures and potential outcomes over time. Always longitudinal, can be prospective (the study begins before the onset of a condition) or retrospective (the study begins after the onset of a condition).

Cross-sectional design

Design in which the participants are assessed at a single time point. It can be useful to identify correlations between variables, but it offers no insight into causality.

Experimental design

Design which involves the manipulation of independent variables in order to scientifically test hypotheses by measuring an effect (dependent variable), such as whether an intervention or treatment is more effective than placebo or no intervention.

Feasibility study

A study of whether an intervention or treatment is appropriate for further testing, i.e., whether it is applicable in practice, relevant and sustainable. Often used in the form of small pilot studies prior to funding large full-scale RCTs.

Longitudinal design

Design in which the participants are assessed at multiple time points. It offers insight into causality, but it increases costs, duration, and drop-out rates.

Meta-analysis

Form of systematic review which analyses the combined outcomes of previous research studies in order to derive conclusions about the chosen subject based on the overall body of literature.

Qualitative study

Design collecting qualitative (non-numerical) data, such as transcripts collected through focus groups and one-to-one interviews. The data analysis is non-objective, influenced by the researcher's analytic stance, their integrative skills and their personal background and knowledge of social context relevant to the material.

Quasi-experiment

Experimental design in which the participants of the experimental and control groups are arbitrarily assigned to the experimental conditions. It is controlled, but not randomised. It is often used when practical or ethical issues prevent randomisation.

Randomised controlled trial (RCT)

Experimental design which compares groups on new condition (e.g., new treatment) with another (e.g., current standard) or no condition (placebo), acting as control. The participants are randomly assigned to the experimental or control conditions, thus making it both controlled and randomised. It represents the highest level of empirical evidence for a single study.

Secondary analysis

Reanalysis of data from a prior study, using different hypotheses or analyses in order to generate new information from the existing dataset.

Single-case experimental design

A form of experimental design which tests the effect of an intervention using a single or very small number of patients.

Uncontrolled pretest-posttest

Experimental design in which a single group of participants is assessed before and after the administration of a treatment, without the inclusion of a control group.

APPENDIX E

ACRONYMS AND ABBREVIATIONS

ACC	Augmentative and alternative communication
ACT	Acceptance and commitment therapy
AES	Apathy Evaluation Scale
ALS	Amyotrophic lateral sclerosis
ALSAQ	Amyotrophic Lateral Sclerosis Assessment Questionnaire
ALSSQoL-R	ALS-Specific Quality of Life Revised
APPG	All-Party Parliamentary Group
BPI	Brief Pain Inventory
BPST-PD	Brief psychosocial therapy for Parkinson's disease
BRS	Brief Resilience Scale
BRT	Behavioural relaxation training
CBT	Cognitive behavioural therapy
CBTi	Cognitive behavioural therapy for insomnia
CDMSC	Chronic Disease Self-Management Course
CFT	Compassion focused therapy
CGI	Clinical Global Impression scale
CIS	Clinically Isolated Syndrome

CNS	Central nervous system
CPAQ-8	Chronic Pain Acceptance Questionnaire
CR	Cognitive restructuring
CR-HYP	Combined hypnosis-cognitive restructuring
CST-PD	Cognitive stimulation therapy for Parkinson's disease
DASS	Depression, Anxiety and Stress Scale
DBT	Dialectical behaviour therapy
DLB	Dementia with Lewy bodies
DT	Dignity therapy
EDS	Excessive daytime sleepiness
EMDR	Eye movement desensitisation and reprocessing
FEEL	Feeling Experiences Enriches Living
FKV-LIS	Freiburg disease coping questionnaire
HADS	Hospital Anxiety and Depression Scale
HD	Huntington's disease
HDA	Huntington's Disease Association
HEP	Health enhancement program
HRQoL	Health-related quality of life

HTT	The Huntingtin protein
HYP	Self-hypnosis training
IAPT	Improving Access to Psychological Therapies
ICD	Impulse control disorder
MBCT	Mindfulness-based cognitive therapy
MBSR	Mindfulness-based stress reduction
MMBCEP	Mindfulness meditation-based complex exercise program
MND	Motor neurone disease
Mood-VAS	Visual Analogue Scale
MRI	Magnetic resonance imaging
MS	Multiple sclerosis
MSQOL-54	Multiple Sclerosis Quality of Life measure
MST	Multi-component sleep therapy
MusiQoL	Multiple Sclerosis International Quality of Life measure
NICE	The National Institute for Health and Care Excellence
NPI	Neuropsychiatric Inventory
OCD	Obsessive-compulsive disorder
OQ-45	Outcome Questionnaire

PCS	Pain Catastrophizing Scale
PD	Parkinson’s disease
PD-CST	Cognitive stimulation therapy for Parkinson’s disease
PDD	Parkinson’s disease dementia
PD-MCI	Mild cognitive impairment in Parkinson’s disease
PDP	Parkinson’s disease psychosis
PDQ-8	Shortened Parkinson’s Disease Questionnaire
PDQ-39	Parkinson’s Disease Questionnaire
PDSS	Parkinson’s Disease Sleep Scale
PEP-HD	Patient Education Program for Huntington’s disease
PP-HD	Psychoeducational program for people with HD
PPMS	Primary progressive MS
PRMS	Progressive-relapsing MS
PSS	Perceived Stress Scale
PTSD	Post-traumatic stress disorder
pwHD	Person or people with HD
pwMND	Person or people with MND
pwMS	Person or people with MS

pwPD	Person or people with PD
QoL	Quality of life
RBD	REM sleep behaviour disorder
RCT	Randomised controlled trial
READY	Resilience for Adults Everyday
REM	Rapid eye movement
RIS	Radiologically Isolated Syndrome
RLS	Restless leg syndrome
RmT	Remotivation therapy
RRMS	Relapsing-remitting MS
RS-15	15-item Resilience Scale
SAS	Social Adjustment Scale
SFET	Self-focused exposure therapy
SF-12	Short-form 12 item health survey
SF-36	Short-form 36 item health survey
SIGN	Scottish Intercollegiate Guidelines Network
SPMS	Secondary progressive MS
SSMWD	Stress Self-Management for Women with Disabilities

SSRIs	Selective serotonin reuptake inhibitors
STN-DBS	Subthalamic nucleus deep brain stimulation
TAPS	Telephone-administered peer support
TAU	Treatment as usual
T-CBT	Telephone-administered CBT
T-SEFT	Telephone-administered supportive emotion-focused therapy
WCC	Ways of Coping Checklist
WHOQOL	World Health Organisation Quality of Life measure

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APPENDIX F

LIST OF IDENTIFIED REVIEWS

Huntington's disease

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