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Professional Practice Board

Psychological services for people with Parkinson's disease

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Executive Summary

Parkinson's disease (PD) affects thousands of people in the UK; the impact of the condition on individuals and their families can be devastating. Great progress has been made in the management of the motor symptoms of PD, but until recently comparatively little attention has been paid to the emotional and psychological impact of the condition (Dobkin, Allen & Menza, 2006). Pharmacological and medical interventions can make a positive impact on some of the mood problems associated with PD (Truong, Bhidayasiri & Wolters, 2008), but more research needs to be undertaken on the effectiveness of pharmacological and non-pharmacological interventions, particularly for depression, anxiety and psychosis. Effective evidence-based psychological interventions must be made available to people with PD who experience psychological disorders. Furthermore, the cognitive sequelae of PD need to be more widely recognised and understood. Individuals with PD who experience cognitive difficulties should have access to neuropsychological assessment and intervention.

Key contributions that can be made by clinical psychologists and neuropsychologists in the management of PD include:

- Assessment of mood and adjustment issues;
- Neuropsychological assessment;
- Psychotherapeutic intervention for depression, anxiety and for the management of psychosis;
- Specific interventions to promote psychological adjustment and cognitive rehabilitation;
- Promotion of long-term psychological adjustment;
- Family interventions;
- Dissemination of psychological skills/understanding of PD issues;
- Contributions to service developments and to research;
- Teaching, education and support for clinical and academic staff.

Access to psychological assessment and intervention for people with PD is inconsistent across the UK. Some older adults with PD may have access to generic older adult clinical psychology services, or may receive some psychological assessment or intervention via older adult psychiatric services. However, dedicated PD specialist clinical psychology and neuropsychology services are extremely scarce in the UK. Very few services offer specialist psychological assessment and intervention for younger people with PD who may have quite different unmet psychological needs. The current document highlights the need for further research into the psychological management of emotional and cognitive problems associated with PD, with a view to enhancing the provision of clinical psychology and neuropsychology input to specialist PD services. The various roles that clinical psychologists and neuropsychologists might adopt within specialist PD services are also described.

Introduction

This briefing paper is intended for use both by health and social care professionals working with people who have PD, and also by people with PD and their families. It has four main aims:

1. To outline the psychological consequences of PD and review the evidence base for psychological approaches to intervention.
2. To brief service managers on the potential utility of psychological assessment and intervention within PD services.
3. To provide information on the potential role and function of clinical psychologists and clinical neuropsychologists in the provision of services to PD survivors and their families.
4. To offer recommendations as to how clinical psychology and neuropsychology input may be structured within specialist PD services.

Key Parkinson's disease facts

- Every year approximately 10,000 people in the UK are diagnosed with PD (Schrag, Ben-Shlomo & Quinn, 2000).
- Approximately 120,000 people in the UK are currently living with a diagnosis of PD (MacDonald, Cockerell, Sander & Shorvon, 2000).
- It has been estimated that approximately four million people worldwide have the condition (World Health Organisation, 1998).
- Symptoms can include motor problems (such as tremor, slowness of movement and stiffness or rigidity of muscles) and non-motor problems (such as sleep disturbance, cognitive difficulties and psychological problems such as depression, anxiety and psychosis) (Davie, 2008).
- The nature and severity of the symptoms of PD vary considerably between individuals (Lieberman, 1998).
- Often the non-motor symptoms of PD can be more disabling than the motor dysfunctions (Truong et al., 2008).

Psychological symptoms of Parkinson's disease

The psychological sequelae of PD can be as disabling for an individual as their motor symptoms, and in particular the fluctuation of non-motor symptoms such as anxiety and slowed thinking can be particularly disabling (Witjas et al., 2002). Although many people with PD may not experience significant cognitive impairment or psychological disorders, they and/or their family members may struggle to adjust to the social, emotional and personal changes brought on by the condition. While the motor symptoms may be the most disabling consequences of PD, and, therefore, the appropriate primary target of medical management, the psychological consequences of the condition must also be recognised and addressed. The following is a summary of the psychological features of PD. Individuals with PD are very heterogeneous; there is a full spectrum of psychological experience for people with the condition and any given individual may experience none, some or almost all of the following symptoms.

Cognitive impairment

For some people with PD, cognitive impairment can develop and may cause significant disability (Lieberman, 1998). Some studies suggest that as many as 36 per cent of newly-diagnosed people with PD have one or more areas of cognitive impairment evident on formal neuropsychological assessment (Foltynie, Brayne, Robbins & Barker, 2004). Early cognitive difficulties associated with PD include working memory problems, slowed information processing speed, impoverished learning and recall, and subtle executive dysfunction (Troster & Fields, 2008).

It is important to differentiate between PD with and without dementia. Some people with PD may have cognitive problems without evidence of a significant global dementia (Brown & Marsden, 1988). The most widely accepted prevalence rates for dementia in PD are 20 per cent to 40 per cent (Mohr, Mendis & Grimes, 1995). Early recognition of possible cognitive problems is vital as such problems (especially in the context of possibly impaired motor functioning, depression, anxiety and adjustment difficulties) can severely impact upon the quality of life of the person with PD and that of their family members (Aarsland, Larsen, Karlsen, Lim & Tandberg, 1999). If identified early, neuropsychological rehabilitation strategies may enable the individual to compensate for their cognitive difficulties, remain living in their own home for longer and allow for a greater quality of life for the individual and their family.

There are probably multiple aetiologies for dementia in PD; the neuropsychological profiles of people with PD can, therefore, be quite heterogeneous (Troster & Fields, 2008). It is vital that any detailed cognitive assessment of a person with PD is undertaken by or under the supervision of a qualified clinical neuropsychologist.

The domains of cognition that may be affected in PD include:

- *Executive functioning;* this includes cognitive abilities such as planning, conceptualisation, flexible thinking, insight, judgement, self-monitoring and self-regulation (Troster & Fields, 2008). Troster and Fields (2008) argue that executive functioning is especially important to assess in PD as this relates to the initiation and

realisation of goals, and to issues of capacity and consent (Dymek, Atchison, Harrell & Marson, 2001).

- *Information processing speed;* also referred to as thinking speed, this can be a cognitive feature of PD (Grossman et al., 2002) and can worsen following neurosurgical treatment for motor symptoms of PD (York et al., 2008)
- *Attention;* simple attention tasks such as digit span and spatial span are often intact early in PD (Troster & Fields, 2008). However, working memory (the ability to hold and manipulate information in mind for a short time) can often be impaired even in the early stages of PD (Stebbins, Gabrieli, Masciari, Monti & Goetz, 1999). Other attentional functions, such as divided attention, visual search and attentional set shifting can be affected in PD (Troster & Fields, 2008)
- *Memory;* new learning and free recall can be impaired in PD. Recognition memory can also be impaired (Whittington, Podd & Kan, 2000), although is generally thought to be less affected (Troster & Fields, 2008). The contribution of low mood or depression to the experience of memory problems complicates assessment and intervention (Norman, Troster, Fields & Brooks, 2002) and must be considered in any cognitive assessment. In people with PD without dementia, recall of past information (e.g. knowledge of events prior to the onset of PD) is typically intact (Leplow et al., 1997). In people with PD who develop dementia, remote memory often becomes impaired (Leplow et al., 1997). Prospective memory (i.e. memory for intended future action) has received relatively little attention in the PD literature to date although some studies have suggested that prospective memory can be impaired in PD (Kliegel, Phillips, Lemke & Kopp, 2005).
- *Language;* people with PD who develop dementia can have language problems including impaired naming (Frank, McDade & Scott, 1996) and verbal fluency (Zec et al., 1999), and other subtle linguistic impairments. People with PD without dementia rarely have primary language impairment, but may have some comprehension or expression difficulties due to other cognitive problems such as diminished attention, working memory or information processing speed (Troster & Fields, 2008).
- *Visuospatial/visuoperceptual functioning;* deficits in visual perception can be the earliest cognitive impairments evident in Pakinson's (Troster & Fields, 2008), and may be secondary to other cognitive problems such as impaired attention, motor functioning, or information processing (Brown & Marsden, 1986). Route-finding, drawing, and face recognition may be affected (Pirozzolo, Hansch, Mortimer, Webster & Kuskowski, 1982) in addition to other visuoperceptual/visuospatial functions.
- *General intellectual functioning;* intelligence tends to be unaffected in PD unless dementia develops (Troster & Fields, 2008).

To date, there have been only a few randomised controlled trials investigating the effectiveness of pharmacological treatment for cognitive problems in PD (Samuel, Maidment, Boustani & Fox, 2006). These have shown some modest benefit of treatment with cholinesterase inhibitors such as donepezil and rivastigmine, but significant adverse reactions such as nausea, vomiting and worsening motor symptoms (e.g. tremor) have led to recommendations that these agents should only be used with caution and careful monitoring in PD (Samuel et al., 2006).

Reaction to physical illness and disability

The quality of life of people with PD has been shown in some studies to be more influenced by a person's psychological adjustment to their illness and disability than by the severity of the disease itself (Suzukamo, Ohbu, Kondo, Kohmoto & Fukuhara, 2006). The suggestion of an association between quality of life and psychological adjustment in PD is unproven to date; future research could usefully evaluate this possible link. There is a strong association between quality of life and depressed mood in PD (Aarsland, Larsen, Karlsen et al., 1999). This suggests that clinicians, in addition to the priority management of motor and other medical symptoms, should usefully focus on treating depression in PD as a key component of a holistic package of care. Members of multidisciplinary teams may well already utilise counselling and other psychological techniques; future research should further investigate the effectiveness of these approaches and the utility of psychological intervention in PD.

Mood disorders

Troster and Fields (2008) highlight the problems inherent in diagnosing mood disorders in PD due to the overlap of symptoms between PD and disorders such as depression and anxiety. Within the main psychiatric diagnostic criteria (American Psychiatric Association, 2000), there are separate classifications for mood disorders attributable to medical conditions, including PD. One danger inherent in this approach is that it might be erroneously assumed that treatment of PD will also successfully ameliorate any mood symptoms (Troster & Fields, 2008). As a result, and also because anxiety and depression frequently go unrecognised by clinicians treating PD (Shulman, Taback, Rabinstein & Weiner, 2002), mood disorders such as depression are under-treated in PD (Weintraub, Moberg, Duda, Katz & Stern, 2003).

Non-pharmacological treatments for mood disorders associated with PD are extremely under-researched (Frisina, Borod, Foldi & Tenenbaum, 2008). Given the evidence of adverse side-effects (Ceravolo et al., 2000), or ineffectiveness (Wermuth & Bech, 2006) of pharmacological anti-depressant treatments in PD, further research into alternative non-pharmacological psychological interventions is urgently needed (Ghazi-Noori, Chung, Deane, Rickards & Clarke, 2003). Some pilot programmes into the effectiveness of cognitive-behavioural therapy for depression in PD have recently begun (e.g. Carter & Hannah, The Oregon Health and Science University).

- *Depression:* the prevalence of depression in PD is estimated at between 30 and 40 per cent (Cummings, 1992). However, as few as 20 per cent of depressed people with PD receive treatment (Starkstein, Preziosi, Bolduc & Robinson, 1990). The undertreatment of depression in PD may be due to diagnostic problems (related to the overlap of medical and psychological symptoms), overshadowing concern for physical symptoms, or because successful treatment of depression in PD is challenging due to the potential side-effects and interactions of anti-depressant medication (Frisina et al., 2008). Some of the diagnostic challenges are being addressed, and a recent review of depression rating scales recommends the use of adjusted cut-off scores and the concurrent use of measures to assess the severity of motor symptoms, for example the Unified Parkinson's Disease Rating Scale (Fahn & Elton, 1987), when using rating scales for depression in PD (Schrag et al., 2007).

The delayed treatment of depression in PD will result in significantly reduced quality of life for the person with PD and also their carers/family members (Aarsland, Larsen, Karlsen et al., 1999). A recent randomised controlled trial of antidepressant medication in PD found evidence of a beneficial effect of nortriptyline on depressive symptoms but not for paroxetine CR as compared with placebo (Menza et al., 2008). Further research into the accurate diagnosis and treatment of depression in PD is necessary (Frisina et al., 2008).

- *Anxiety:* According to a recent review, generalised anxiety, agitation, panic attacks and phobic disorders are common in PD, occurring in up to 40 per cent of people with the condition (Hanagasi & Emre, 2005). Depression may co-occur with anxiety disorders, worsening the symptoms (Menza, Robertson-Hoffman & Bonapace, 1993). In common with symptoms of depression, the diagnosis and treatment of anxiety symptoms reportedly receive relatively little attention by clinicians (Hanagasi & Emre, 2005). This is despite the exacerbation of motor symptoms by anxiety and the potential worsening of anxiety symptoms by antiparkinsonian medication (Vazquez, Jimenez-Jimenez, Garcia-Ruiz & Garcia-Urra, 1993). A recent review concludes that none of the commonly used anxiety rating scales have proven validity for use with PD (Leentjens et al., 2008).

  Anxiety disorders may be related to neurochemical changes in the brainstem dopaminergic, noradrenergic, or serotoninergic neurons (Hanagasi & Emre, 2005). Pharmocological treatment of anxiety disorders in PD tends to rely on benzodiazepines such as diazepam, which are generally poorly tolerated by people with PD, potentially causing or worsening confusion and deterioration in motor functioning (Hanagasi & Emre, 2005). Longer-term treatment with benzodiazepines can also result in dependency and withdrawal effects when discontinued (Hanagasi & Emre, 2005).

Psychosis

Psychosis is one of the most disabling and distressing symptoms of PD (Hanagasi & Emre, 2005), and of PD treatment, occurring in 15 to 25 per cent of people with PD on chronic dopaminergic treatment (Aarsland, Larsen, Cummins & Laake, 1999). Up to 50 per cent of people with PD may experience mild psychotic symptoms such as non-threatening visual illusions or ideas of presence (Hanagasi & Emre, 2005). Those people who experience more severe psychotic symptoms such as threatening hallucinations or delusions are at greater risk of placement in a nursing home (Aarsland, Larsen, Tandberg & Laake, 2000). People with PD who develop dementia are significantly more likely to have psychotic symptoms (Samuel et al., 2006).

The diagnostic process is complex due to the overlap of psychotic symptoms in people with PD who develop dementia and in people who have dementia with Lewy bodies (Aarsland, Ballard, Larsen & McKeith, 2001). The frequency of hallucinations is greater in dementia with Lewy bodies (Aarsland et al., 2001). The challenges of treatment are exacerbated by the reported potential adverse impact of antipsychotic medication on the motor symptoms of PD (Ondo, Levy, Vuong, Hunter & Jankovic, 2002). Treatment for the motor symptoms themselves also has the potential to trigger psychotic symptoms (Nilsson, 2004) although the exact mechanism for this is unclear (Samuel et al., 2006).

Pharmacological treatment for psychosis associated with PD is currently unsatisfactory and in need of further research (Samuel et al., 2006). Given the evidence for the beneficial effects of non-pharmacological approaches to the treatment or management of psychosis in other populations, for example, cognitive behaviour therapy (CBT) for psychosis in schizophrenia (Turkington, Kingdon & Weiden, 2006), research into the potential efficacy of non-pharmacological approaches to the management of psychosis in PD is recommended.

Sleep disorders

Sleep disorders have been associated with PD since the condition was first identified (Truong et al., 2008). As with the motor and other non-motor symptoms of the condition, sleep disorders have a complex aetiology in PD (Truong et al., 2008). Prevalence estimates indicate that up to two-thirds of people with PD have sleep disturbance (Tandberg, Larsen & Karlsen, 1998), with approximately one-third of people with PD reporting moderate to severe sleep problems. Specific sleep disorders associated with PD include insomnia, hypersomnia, parasomnia, and rapid eye movement (REM) sleep behaviour disorder (Truong et al., 2008). The aetiology of nocturnal sleep disruption is likely to be multifactorial for any individual patient with PD. This is a related but distinct condition from excessive daytime somnolence; there is some evidence that psychostimulants such as modafinil can be effective in treating excessive daytime somnolence (Ondo, Fayle, Atassi & Jankovic, 2005).

As with other non-motor symptoms of PD, sleep disorders can be under-recognised and, therefore, under-treated by clinicians (Shulman et al., 2002). In addition to pharmacological treatment, sleep hygiene psycho-education can be effective in helping people manage the impact of sleep disorders (Truong et al., 2008). Cognitive behavioural approaches to management of sleep problems may also be effective (Morin, 1993).

Fatigue

Fatigue is one of the most common, distressing and disabling non-motor symptoms of PD. There is currently no pharmacological treatment and modafinil is ineffective (Ondo et al., 2005). Cognitive behavioural approaches have been successfully used to manage fatigue related to other conditions such as chronic fatigue syndrome (Price, Mitchell, Tidy & Hunot, 2008) and this is an area in which a significant impact might potentially be made in the management of PD. Future research should evaluate the potential benefit of CBT and other psychological interventions in the management of fatigue in PD.

Neurobehavioural disorders

Pharmacological treatment for some people with PD has been associated with the development of neurobehavioural problems such as hypersexuality, preoccupation with complex motor acts such as disassembling electrical equipment, hypomania and mania, aggression and heightened irritability, an urge to walk considerable distances without purpose, pathological gambling and shopping, and food cravings (Troster & Fields, 2008). These complex problems require detailed assessment and diagnosis by specialist PD services, with input from psychiatrists and/or clinical psychologists.

Needs of Carers/Family members

As with most chronic illnesses, the major burden of informal care is most often borne by the spouse and family members of the person with PD (Secker & Brown, 2005). Care responsibilities including physical demands can be very significant (Carter et al., 1998) and the personal, emotional, social and financial impact of PD on carers and family members can be huge. The change in relationships between people with PD and their spouses can be very distressing for all concerned, and it is, therefore, not surprising that care-giving can adversely affect the physical and psychological health of the carer (Secker & Brown, 2005).

Psychological models of stress in family care-giving (Pearlin, Mullan, Semple & Skaff, 1990) highlight the importance of reducing stress proliferation and introducing or enhancing strategies for stress containment (Secker & Brown, 2005). There is preliminary evidence that cognitive-behavioural therapy based on these principles is an effective approach in the management of psychological morbidity in carers of people with PD (Secker & Brown, 2005).

The potential value of collaborative approaches to the management of psychological distress in carers of people with PD is an important area of new research. For example, group interventions developed by clinical psychologists, and run by Parkinson's disease Specialist Nurses who are trained and supervised by clinical psychologists, may be one of the most cost-effective approaches to addressing the psychological needs of carers/family members. One such intervention, currently under investigation, is the Parkinson's Disease Society/Edmond J. Safra Foundation funded 'Caring for Carers' research study, under the leadership of Professor Richard Brown, Institute of Psychiatry, King's College, London.

The role of Clinical Psychology and Neuropsychology

Qualified clinical psychologists/neuropsychologists offer a flexible range of skills including assessment, psychological formulation, direct treatment or intervention, consultation, clinical supervision, and teaching (Kneebone et al., in press). The focus of their knowledge base is on reaching a psychological understanding of an individual's behaviour, thoughts and feelings, and to use this formulation to guide maximally effective interventions (Kneebone et al., in press). Clinical psychologists also possess applied research skills, having undertaken research training to a doctoral level.

Many clinical psychologists working with people who have PD will also possess further specialist knowledge and training in clinical neuropsychology (e.g. the Practitioner Full Membership Qualification (PFMQ) of the British Psychological Society Division of Neuropsychology). This is a necessity for any professional undertaking detailed neuropsychological assessment with people who have PD.

Other professionals (e.g. occupational therapists) may be qualified to undertake some cognitive screening of people with PD and to provide recommendations for adaptations to people's homes and strategies for compensating for cognitive difficulties. However, detailed cognitive assessment should only be undertaken by or under the supervision of an appropriately qualified clinical psychologist/neuropsychologist.

The value of multidisciplinary services for people with PD is dependent upon excellent communication and team-working, and also upon the skill mix of the team. Specialist PD services must include physiotherapists, occupational therapists, Parkinson's disease nurse specialists, dieticians, and neurologists/physicians as core members of the team. In order to address the non-motor symptoms of PD, specialist teams should also have ready access to clinical psychology and neuropsychology services and to older adult psychiatric services.

The interventions listed below are an indication of the range of activities that have been undertaken by clinical psychologists/neuropsychologists working with people who have PD.

Neuropsychological assessment

Clinical neuropsychology is one of the most developed and formalised fields of applied psychology (Bieliauskas, 2008). One of the defining characteristics of a clinical neuropsychologist is the ability to design, perform and interpret neuropsychological tests that have been tailored to the individual being assessed (Smith, Ivnik & Lucas, 2008). Accurate neuropsychological assessment relies upon the psychometric properties of neuropsychological tests in order to differentiate normal from abnormal cognitive performance. Clinical neuropsychologists must, therefore, be well trained in the administration and particularly in the statistical and clinical interpretation of neuropsychological test results (Anastasi & Urbina, 1997).

In PD the primary aim of neuropsychological assessment will typically be to establish the cognitive strengths and weaknesses of the person with the condition. It will often be particularly important to determine whether there is any evidence of dementia. If dementia is present, differential diagnosis between PD with dementia and dementia with Lewy bodies may be relevant, and neuropsychological assessment can contribute to this (Troster & Fields, 2008).

Neuropsychological assessment is particularly important for individuals who are being considered for neurosurgical treatment of their motor symptoms (Burn & Troster, 2004). In the UK neurosurgery may sometimes involve ablation (the surgical removal of brain tissue), or more likely will involve deep brain stimulation (DBS; unilateral or bilateral implantation of electrodes and the application of high frequency electrical stimulation from an implanted pulse generator to the thalamus, globus pallidus or subthalamic nucleus of the brain) (Troster & Fields, 2008). Although DBS procedures are generally thought to involve little risk of significant cognitive impairment, some studies have shown some changes post-operatively in attention, memory or executive functioning (Deuschl et al., 2006). People with pre-surgical cognitive deficits may be at greater risk for neurobehavioural morbidity after subthalamic nucleus deep brain stimulation, and some neurobehavioral disorders have been identified post-surgery (Troster & Fields, 2008). It is, therefore, imperative that candidates for neurosurgery undergo pre-surgery psychological and neuropsychological evaluation.

Neuropsychological rehabilitation

Neuropsychological assessment will inform the person with PD, and the professionals working with the person, as to the nature and extent of their cognitive difficulties. Crucially, the assessment will also help the specialist team to devise and implement rehabilitation strategies. Although PD is a chronic, progressive condition, cognitive rehabilitation strategies may help people to compensate for their cognitive problems, experience a much greater quality of life, and prevent or delay nursing or residential home placement. Additionally, cognitive rehabilitation strategies may help to reduce the burden of care on spouse or family members, and alleviate caregiver stress.

Psychosocial adjustment

Psychosocial adjustment to PD depends on the interaction of cognitive, behavioural, physical, personality and social factors. Psychological assessment can enable clinicians to formulate an understanding of the factors that might hinder a person's adjustment to PD, and will inform psychological and multidisciplinary interventions. There is a relative dearth of research into the effectiveness of strategies aimed at facilitating psychosocial adjustment (Visser et al., 2008); future research should focus on the application and evaluation of such strategies in order to develop evidence-based psychological interventions. Existing interventions which promote psychosocial adjustment to other neurological conditions (e.g. multiple sclerosis, stroke) might usefully be adapted for use in PD.

Psychotherapeutic intervention

Psychotherapy for primary depression and anxiety disorders is a widely accepted treatment option (National Institute for Health and Clinical Excellence, 2007). In particular, cognitive-behavioural therapy (CBT) for depression in older adults (Laidlaw et al., 2008) has been proven to be an effective evidence-based treatment (Arean & Cook, 2002). Given the high prevalence of mood disorders in PD, and the problematic pharmacological treatment of these symptoms (Wermuth & Bech, 2006), it is imperative that further research is undertaken into the potential benefit of psychotherapy for depression and

anxiety disorders in PD (Dobkin, Allen & Menza, 2007). Preliminary studies into the potential effectiveness of cognitive behavioural therapy for depression in PD have suggested that this intervention can be of significant benefit to some people with the condition (Dobkin et al., 2007). Treatment packages have been developed (Dobkin et al., 2006), and many clinical psychologists working with older adult populations in the UK will use cognitive behavioural and other psychotherapeutic models to inform effective psychological interventions for their clients who have PD.

Cole and Vaughan (2005), in their review of the feasibility of using a cognitive behavioural therapy for depression in PD, highlight the evidence in support of CBT for depression in older adults who have chronic illnesses other than PD. Although there are challenges associated with adapting psychotherapy for these populations, there is considerable evidence for the effectiveness of psychological treatment (Cole & Vaughan, 2005). Psychological interventions other than CBT, for example, cognitive-analytic therapy (Hepple & Sutton, 2004) may also have considerable potential for application with people who have mood disorders associated with PD. Clinical psychologists and neuropsychologists are ideally placed to assess people for their suitability for psychotherapy and to supervise or undertake these psychological interventions.

Addressing the needs of Carers

Most people with PD live in their own homes and, as significantly disabling symptoms develop, are cared for by their spouse or other family members (Secker & Brown, 2005). Carers who develop significant levels of stress are vulnerable to psychological disorders such as depression and should have access to psychological support and intervention. Psychotherapy for carers of people with PD (e.g. CBT) is supported by preliminary evidence (Secker & Brown, 2005).

Clinical psychologists and neuropsychologists have high levels of expertise in using psychological interventions and are well placed to offer the range of services above, to a high standard, taking into account the complex interaction of motor symptoms, mood disorders, cognitive impairment, and other potential factors such as neurobehavioral disorders, psychosis and sleep disorders. Working within or in close collaboration with other professionals in specialist PD services, clinical psychologists and neuropsychologists can make significant contributions to the psychological health and quality of life of people with PD and their carers/family members. Psychologists are also well placed to develop and initiate research into the effectiveness of psychosocial and psychotherapeutic intervention in people with PD, and can also help to monitor and evaluate the effects of pharmacological and neurosurgical interventions. Models of service delivery might include the clinical psychology/neuropsychology supervision of Parkinson's disease Nurse Specialists providing group interventions for people with PD and their carers.

Recommended Psychological services for people with Parkinson's disease

Service specification

Many existing specialist services for people with PD will have access to counselling/psychological support/pharmacological treatment from nurses or psychiatrists. Relatively few are thought to have psychologists as core members of the multidisciplinary team, in stark contrast with many services developed for people with Alzheimer's disease, in which clinical psychologists/neuropsychologists often play a central or lead role in the management of teams and in the development and delivery of clinical services. Pilot projects to assess the potential benefit of dedicated specialist clinical psychology/neuropsychology input into PD teams are strongly recommended. Rapid access to psychological and neuropsychological assessment and formulation, and psychotherapeutic intervention and neuropsychological rehabilitation, could significantly benefit people with PD and their families; the potential benefit of these services should be assessed. Quality of life arguments are obvious in terms of reducing psychological distress and morbidity, and caregiver burden, and in adhering to NHS National Service Framework quality targets for person-centred, specialist rehabilitation (Department of Health, 2005). Cost effectiveness could also usefully be evaluated in terms of reduced hospital admissions and length of stay, and in delaying or preventing residential or nursing home placement.

We recommend that people with PD have access to the following services:

- Specialist multidisciplinary PD clinics with dedicated input from clinical psychologists or clinical neuropsychologists.
- Specialist multidisciplinary neurorehabilitation units with dedicated input from clinical psychologists or clinical neuropsychologists.
- Specialist multidisciplinary neuro-outreach services with access to clinical psychologists or clinical neuropsychologists.

Given widespread resource constraints and the national shortage of clinical neuropsychology posts in the UK, local service provision models may rely on the provision of psychotherapeutic intervention or cognitive screening by non-psychologists such as appropriately qualified counsellors, specialist nurses or occupational therapists. Such services should only be provided under the supervision of clinical neuropsychologists with specialist training. Formal neuropsychological assessment of people with PD should only be undertaken by qualified clinical neuropsychologists.

Where clinical psychologists/neuropsychologists are not embedded within multidisciplinary teams, greater links are required between neurology services and local mental health services. Community mental health teams are typically overwhelmed by chronic and severe psychiatric disorder and rarely have the resources to devote to 'medical' conditions. Equally, psychologists working in primary care may feel that they lack the necessary training and experience to tackle mental health problems in patients with co-morbid neurological disorders. New developments in service provision could include

psychiatric/psychological liaison services for people with non-dementia neurological disorders. Additionally, increased training for clinical psychologists and cognitive behavioural therapists who wish to work with these client groups is recommended. Psychologists should also be available to work collaboratively with occupational therapists who are undertaking home-based interventions with people with PD.

Service ethos

Providers of psychological services for people with PD will understand the chronic nature of the condition and must, therefore, recognise that individuals' psychological difficulties will change over the course of the condition. Clinicians must avoid the 'assessment-discharge' model of service provision (Bender & Wainwright, 2005). Instead, psychological assessment and intervention must be available along the entire patient pathway from diagnosis to the palliative stage of care. Service provision should allow for holistic assessment, place the person within a social context, allow rational planning of services on an individual level, and encourage proactive monitoring of care and adaptation of provision as the needs of the person change over time (Bender & Wainwright, 2005).

Service standards

British Psychological Society (BPS) briefing papers on purchasing clinical psychology services for older people, their families and other carers (BPS Division of Clinical Psychology, Briefing Paper No. 5) and for people with acquired neurological disorders and their carers (BPS Division of Clinical Psychology, Briefing Paper No. 9) have been published. These both set out an appropriate care philosophy and standards, to which the reader is referred.

Services for younger people with Parkinson's disease

Approximately 5 to 10 percent of people diagnosed with PD are under the age of 40 (Golbe, 1991). The needs of this subgroup may be different and clinicians may need to consider the implications of possibly more significant and immediate occupational, financial, and family responsibilities. The psychological assessment and management of younger people with PD should nevertheless adopt a similar ethos as that provided to older people with the condition: each individual should receive services tailored to their specific needs.

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