Title: What can the treatment of Parkinson's disease learn from dementia care; applying a bio-psycho-social approach to Parkinson's disease**.**

Background. Within contemporary medical practice Parkinson's Disease (PD) is treated using a biomedical, neurological approach, which although bringing numerous benefits can struggle to engage with how people with PD experience the disease. A bio-psycho-social approach has not yet been established in PD, however bio-psycho-social approaches adopted within dementia care practice could bring significant benefit to PD care.

Methods. This paper summarises existing bio-psycho-social models of dementia care, and explores how these models could also usefully be applied to care for PD. Specifically, this paper adapts the bio-psycho-social model for dementia developed by Spector and Orrell (2010), to suggest a bio-psycho-social model which could be used to inform routine care in PD.

Results. Drawing on the biopsychosocial model of Dementia put forward by Spector & Orrell (2010), this paper explores the application of a bio-psycho-social model of PD. This model conceptualises PD as a trajectory, in which several inter-related fixed and tractable factors influence both PD's symptomology and the various biological and psychosocial challenges individuals will face as their disease progresses. Using an individual case study, this paper then illustrates how such a model can assist clinicians in identifying suitable interventions for people living with PD.

Conclusion. This model concludes by discussing how a bio-psycho-social model could be used as a tool in PD's routine care. The model also encourages the development of a theoretical and practical framework for the future development of the role of the PD specialist nurse within routine practice.

Implications for practice. A biopsychosocial approach to Parkinson's Disease provides an opportunity to move towards a holistic model of care practice which addresses a wider range of factors affecting people living with PD. The paper puts forward a framework through which PD care practice can move towards a biopsychosocial perspective. PD specialist nurses are particularly well

placed to adopt such a model within routine clinical practice, and should therefore be encouraged within PD services.

Keywords. Parkinson's Disease. Dementia. Bio-psycho-social model. Parkinson's Disease Nurse Specialist

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Summary Statement of implications for practice

What does this research add to existing knowledge in Gerontology?

- This research shows how theoretical perspectives developed within dementia care research can usefully be applied to the care of people with Parkinson's Disease.
- This research puts forward a bio-psycho-social approach to care for people living with Parkinson's Disease.

What are the implications of this new knowledge for nursing care with older people?

- A biopsychosocial model of PD provides practitioners with a tool through which they can better identify and address the problems people living with PD routinely face.
- Parkinson's Disease nurse specialists are well placed to deliver such a model, but require support to do so.

How could the findings be used to influence policy or practice or research or education?

- This model encourages research to recognise all aspects that PD has on the lives of people living with PD, and encourages a research agenda which addresses their concerns.
- A biopsychosocial model of PD can support the design and development of holistic PD care services.

Introduction

Parkinson's Disease (hereafter PD) is a progressive neurological disorder, of unknown aetiology, which currently affects 10 million people worldwide (Parkinson's Disease Foundation 2013; Pringsheim *et al* 2014). While a neurological and pharmacological approach to PD therapy concerned with motor symptomology can alleviate many of PD's symptoms, this treatment model also encourages an under-recognition and under-treatment of many of PDs most distressing experiences, leading to gaps between clinical priorities and patient need (Gibson 2016). This paper argues that the bio-psycho-social approaches developed within dementia care research can contribute much to PD's routine care [Downs et al 2008; Spector & Orrell 2010). By adapting models of care used in dementia to PD, PD's routine care can better recognise the full range of patient's experiences as well as those prioritised within neurological approaches to PD therapy (Playfer 2007). After examining the medical models of PD and dementia and its critiques, this paper draws on a case study to explore how a bio-psycho-social model can be applied to PD, and the implications such an approach may have for PD's routine care.

Explanatory models; PD and Dementia

The Psychiatrist and Anthropologist Arthur Kleinman's concept of explanatory models provides a means to conceptualise how illnesses are differentially defined, perceived and treated by practitioners, patients and society at large (Kleinman 1988). Although the predominant explanatory model for an illness offers a shared perspective through which an illness may be understood, how these models are interpreted differs significantly between clinicians and patients. Such differences lead to significant gaps between what clinicians identify as their priorities and patients own experiences (Downs et al 2006). Appreciating these differing explanatory models therefore provides clinicians with a means of better understanding their patient's experiences and how they may differ from their own perspectives. In doing so, Kleinman's original concept can assist clinicians in better identifying and addressing patient need.

Based in neurology, the most commonplace explanatory model for PD within medicine conceptualises the disease as the breakdown of striatal dopamine, manifested through the progressive development of motor symptomology and treated through dopaminergic and related therapies (Playfer 2007). This mono-disciplinary model has been criticized for under-recognising and under-treating much of PD's symptomology (Van Der Marck et al 2009; Gibson 2016). Greater attention is now being paid to PD's non-motor symptomology within routine care, inclusive of symptoms such as dementia (Aarsland et al 2005), mood disorders (Leentjens 2004), hallucinations (Gibson et al 2013), impulse control disorders (Wu et al 2009), or the side effects of dopaminergic therapies (Matson 2002). Questions have also been raised regarding the relative impacts of PD's symptoms on quality of life, with research showing that PD patient's complaints diverge significantly when compared to those symptoms prioritised in PD's routine therapy (Tickle-Degnen & Doyle Lyons 2004). For example, while patients highlight mental, functional and psychosocial impairments as their biggest problems, clinicians routinely judge motor symptoms which respond to anti-Parkinson's drugs as most distressing (Abudi et al 1997, Rahman et al 2008, Politis et al 2010). Although useful for identifying and addressing disease pathology, PD's conceptualisation within medicine therefore differs greatly when compared to patient's judgements about PD, leading to significant differences between clinical priorities and patients lived experiences.

Rahman *et al* argue for a paradigm shift in PD therapy, comprising a move away from a singular focus on motor symptoms towards a multi-disciplinary, holistic approach which better reflects the complexity of the problems arising in PD (Rahman et al 2008). However, despite such an approach being previously recommended within national and international guidance regarding PD's routine treatment (Parkinson's UK 2015; Hellqvist & Bertero 2015), such a multi-disciplinary focus has not yet become the norm (Politis et al 2010; Parkinson's UK 2015). This suggests that a shift to more holistic and multidisciplinary models of care has not yet taken place.

The explanatory model for Dementia provides useful insights in relation regarding how such a paradigm shift in PD towards multidisciplinary treatment and holistic care can be encouraged.

Historically the lay model for dementia was 'senility', in which memory losses were viewed as a natural and expected part of older age (Downs et al 2006). Only relatively recently has a neuropsychiatric model of dementia been developed, based on advances in neuroscience and medical imaging which have led to some of the specific disease pathologies leading to dementia being identified (Fox 1989; Downs et al 2006). The growth of this neuropsychiatric model, alongside political concerns about demographic ageing has contributed to the recent dramatic growth in scientific and political concern being paid to dementia, demonstrated in the last decade by increasing international calls for research, such as the UK Prime Minister's challenge for dementia, and the French National Alzheimer Plan.

The neuropsychiatric model of PD has also been robustly criticised. First, it has not yet led to effective therapies. The few dementia drug treatments currently available only have limited or modest efficacies, numerous dementia trials have failed, while what few non-drug treatments are available have either limited evidence for their efficacy or are only rarely offered by services, despite evidence for their effectiveness (Dickinson *et al* 2016). Examples of such non-drug therapies include Cognitive Stimulation Therapy (Spector & Orrell 2006; World Alzheimer Report 2011). The neuropsychiatric model of dementia has also been criticised for holding 'an accompanying tendency to attribute the experience of persons with dementia exclusively to a disease process', thereby ignoring its psychological or social experience [Cotrell & Schultz 1993 pp. 205]. Each of these issues can contribute to poor care practices, leading to calls for more holistic approaches to Dementia Care such as the UK Government's Living Well with Dementia strategy or UK Alzheimer's Society 'Dementia Friends' initiative (Mitchell et al 2016).

The paucity of effective clinical treatments for dementia has arguably given space for alternative explanatory models for dementia to develop. Of greatest significance is the social model of dementia. Exemplars of the social model include Sabat's concern over the self in dementia (Sabat & Harre 1994) and Kitwood's (1997) seminal work on personhood in dementia. Key to the social model of dementia is the postulation that dementia is experienced through the 'interplay of neurological

impairment, physical health, sensory acuity, personality, biography and experience, relationships and social resources' (Kitwood 1997). The various problems associated with dementia, such as memory loss, confusion, agitation or wandering are not simply the result of cognitive breakdown. They are also reflections of a person's shifting ability to make sense of the world. Not just biological change, it is what Kitwood (1997) famously termed 'malignant social psychology' which 'deprives a neurologically impaired individual of their 'personhood', or their socially determined right to exist in the world as individuals' that leads to many of the problems experienced in dementia. To successfully care for those with dementia, dementia care practitioners must therefore show a heightened sensitivity to the place people with dementia occupy in their individual social worlds. This model has also been critiqued, with subsequent developments moving towards a 'rights' based approach to dementia, which calls for people with dementia to be accorded full rights as citizens, fully able to participate in life (Bartlett & O'Connor 2010; World Health Organisation 2015).

Dementia; a biopsychosocial model

FIG 1 HERE

Expanding on the social model, recent work in dementia care research argues for a biopsychosocial approach to dementia (Spector & Orrell 2010, Sabat 2008). This approach argues for a synthesis between medical and social models of illness, and integrates the biological changes and physical, mental and emotional states occurring in dementia with the psychosocial impacts resulting from an individual's changing social environment. Spector and Orrell (2010) integrate the various biopsychosocial approaches in dementia into a single model (fig 1), which they suggest can be used as a tool for understanding individual cases. This model encourages that dementia is recognised as 'something which is malleable and where change, adaptation and improvement is possible' [Downs et al 2008 p959). In doing so, this model moves beyond the separation of the biological and the

social to instead identify the inter-relationships occurring between the two, allowing dementia interventions to be tailored according to individual need.

This model highlights the various biological and psychosocial challenges people face as they move through their illness; from initial symptoms and diagnosis, through disease progression, to end of life care and death. The model includes fixed factors such as age, historic physical health, education level or previous life experiences, and tractable factors which are amenable to interventions, such as mood, current physical health or the actions and reactions of people within an individual's social circle. Finally, the model also recognises how 'excess' disability in dementia results from social practices including medical and social care. By understanding the interplay between biological and psychosocial factors which may influence a person's physical and emotional states, and how these change as individuals move through the illness, this model can be used to inform best practice in dementia therapy and care.

A bio-psycho-social model of PD

FIG 2 HERE

Drawing upon Spector & Orrell (2010) alongside qualitative data from a study of men's experiences of living with PD (Gibson & Kierans 2016; Gibson 2016), this paper puts forward a bio-psycho-social model for PD (fig 2). The qualitative study examined 15 men's accounts of living with PD, the biological and psycho-social factors influencing their experience of PD, and their response to PD as it progressed. Findings from this study are reported elsewhere (Gibson & Kierans 2016; Gibson 2016). Although experiences varied across individuals, several commonalities emerged which contributed to the development of this model. An initial onset of symptoms eventually led to patients seeking a diagnosis, when many men found their most taken for granted assumptions about life changing. With time, most could find ways to integrate the physical, psychological and social changes PD

brought into their lives, drawing on a range of fixed and tractable biological and social factors (listed in fig 2) when doing so.

After undergoing a period of disruption and adaptation early in their illness, most men adopted a circular and iterative approach to coping with PD. As their PD progressed, most men found that their coping strategies began to fail; for example, they could no longer manage long loved hobbies, while even everyday occupations eventually became too difficult for many to accomplish. But people found new ways to cope with these problems. Many involved medicine, for example increasing medication dosages or adding further medications to their regimes to address specific problems. Others were in men's individual social lives and included adapting how they completed their everyday activities, or changing how they interacted with other people (for example taking up less strenuous hobbies or pastimes). These issues each had consequences for men's everyday lives. By finding new ways to adapt to their illness and the problems it caused, several men could successfully cope with their PD. Importantly though, men continually had to adapt their responses to PD's worsening symptoms. This process of decline and adaptation could take place well into disability, however as PD worsened accomplishing these adaptations became more difficult, leaving people potentially vulnerable to both lower quality of life, declining mood and an exacerbation of their PD symptoms if they could no longer adapt to their PD.

At its core, adopting such a model in PD care encourages clinicians to consider PD's effects on the totality of those with PD's lives, and to identify interventions with can help people cope with all the problems they will face. By acknowledging this circular experience medical and psycho-social interventions can be designed which are appropriate to people's individual illness stage and to their changing needs. At the biological or clinical level, such interventions include increasing PD medications or introducing new drug therapies. Interventions at a psychological or psychosocial level may be tailored to help people to cope with the onset of symptoms, to retain everyday occupations, or come to terms with their progressive losses in abilities as their PD worsens. In addition, the

consequences of current interventions, such as the side effects resulting from increasing medication loads can more easily be identified and managed. To explore the utility of adopting a bio-psycho-social approach in PD this paper now turns its attention to 'Tony', a man in middle age living with moderate PD.

Applying a bio-psycho-social approach to PD; the case of 'Tony'

Tony (a pseudonym) was a 62-year-old man with moderate PD, who took part in the qualitative research described above. At the time of interview, Tony had been living with PD for 12 years. Tony also had a history of depression, which forced him to take early retirement. Tony took several PD drugs but noticed that they were becoming less effective, meaning his dosages had to be increased more and more frequently. Tony was also experiencing motor side effects, including 'off periods', where his symptoms suddenly deteriorated at the end of a medication dose, and peak dose dyskinesia's or the involuntary movements associated with dopaminergic therapies (Matson 2002). Consequently, Tony struggled more and more with his various daily activities; he didn't know how much longer he would be able to drive, sail his fishing boat or walk his dogs on the beach near his home. Living in a rural and isolated area, Tony also struggled to drive to his local village to do his shopping, to see his GP, or get to the local PD clinic, 40 miles away. Tony was satisfied with his care team, but struggled to contact his local PD specialist nurse for advice or support when he needed it. Of greatest significance, the increases to his medication dosage, alongside more frequent side effects meant Tony worried about how fast his condition was worsening, what would happen in the future and how much time he had left before his PD got 'bad bad' (Gibson 2016). Also, given his history of depression, Tony particularly feared that his worsening PD could cause another bout of depression, leading him to consider suicide rather than live with both the severe disability and severe depression he feared his PD would bring.

Applying a bio-psycho-social model to Tony's care raises several implications for his PD care. For Tony, it was both declining activities of daily living and increases in medication side effects that posed a threat to his quality of life. Identifying what these impacts may be, and whether therapies could assist Tony's continued social participation should therefore be investigated. Tony had also become very aware of the changes in bodily functioning caused by medications, planning his days around the times when his medications were functioning well. In addition to their beneficial effects, Tony also had to manage a whole range of side effects. Dyskinesia and 'off' periods were both side effects of PD's therapy which Tony had to deal with on a daily basis. Tony had developed extensive knowledge of his medications and their effects over time, using this knowledge to understand and manage his illness. While bringing benefits new medications were also interpreted as a deterioration in his condition, leading Tony to worry about how much worse his condition might get. Decisions about medications should therefore be made in collaboration with the patient, paying attention not only to motor function, but also to how tolerable side effects may be. Furthermore, clinicians should investigate how medication usage is understood by patients, and how medication management influences this experience. In this respect, the biopsychosocial model shows up the need to take greater account of the 'real world' consequences of both PD's symptoms and PD therapy, and the need to involve patients in making informed decisions about their treatments.

Going beyond the pharmacological management of PD, a biopsychosocial model also gives important insights into the inter-relatedness of PD symptoms, PD care and wider health and quality of life. PD should therefore not be treated in isolation, but should be understood within the context of a patient's wider health. Tony gave clear indications of his priorities for treatment. Given Tony linked his depression and PD motor symptoms, importance should be paid to helping Tony manage his depression within the context of his PD. In addition, helping Tony manage and come to terms with his body's physical decline and the commensurate loss of hobbies, pastimes and other activities

linked to a sense of self should also be priorities for his care. Such forms of support should reflect a concern for PD's effects within the context of Tony's life and lived experience.

In the case of Tony, pharmacological therapies can be complemented by psycho-social interventions such as physiotherapy, psychotherapy or occupational therapy, each at appropriate stages of his illness. Psychotherapy can help manage expectations over bodily decline as well as mood disorders associated with PD (Brown et al 2011). In conjunction with medications physiotherapy can assist with supporting physical movement (Tomlinson *et al* 2013). Occupational therapy services are well placed to assist with occupations; either through using assistive technologies, aids and adaptations, or simply in supporting people with PD to carry out daily tasks (Dixon *et al* 2007; Foster *et al* 2014). More widely, a bio-psycho-social model helps to identify periods during an individual's illness where assistance may be more necessary. Within men's accounts of living with PD, three points of disjuncture become prominent, in which careful attention to patient experience is required. First during and in the initial period of diagnosis, as people first experience a deterioration in function after commencement of treatment (the end of what Solimeo 2008 calls the medication honeymoon) and when medications begin to lose their overall effect, or when side effects start to become intolerable. By paying attention to the totality of a person's experience, such a model can assist clinicians in providing both more holistic forms of care, and more personalised therapies better suited to address individual patients' needs.

Conclusion

A bio-psycho-social approach provides a means through which we can gain greater insights into PD's experience, which better reflect patient's needs. This model does however have several limitations. The empirical work used in the application of this model to PD is limited to a qualitative study of 15 men's experiences of PD. This small and unrepresentative sample therefore limits its generalizability. Further refinement which demonstrates the model's relevance among different

patient groups, for example with women with PD or people of differing ages is also necessary. The applicability of bio-psycho-social approaches drawn from dementia care to PD can also be questioned. Despite a significant degree of overlap in symptoms and age profiles PD and dementia are separate illnesses with their own aetiologies, symptomologies, effects and courses. While the structure of the model bears similarities, the actual processes or activities which drive PD's experiences will be different, as will be the solutions. There is also significant overlap between the factors identified in this model, with physical activities such as dance crossing over multiple fixed and tractable factors (Spector & Orrell 2010; McGill *et al* 2014). Although emerging from empirical research, this model has also not been tested empirically, so the factors which may contribute to wellbeing in PD may well be distinct compared to those listed in this model. Future research applying the model to nursing practice will help identify how such a model could best be implemented within routine care, alongside which factors are most relevant, and which may be most amenable to change.

Despite these limitations, the bio-psycho-social model of PD detailed above is one avenue through which Rahman *et al*'s (2008) paradigm shift towards holistic PD care can be accomplished. It is important to note that this model does not seek to replace a biological and neurological model of PD; such a model remains the best structure through which future therapies for PD will be achieved. However, the strength of adopting a bio-psycho-social approach to PD is that it encourages a greater appreciation of the psychological and social factors associated with the disease, which continue to be under-recognised within its care (McGill *et al* 2014). As multi-disciplinary treatment of PD has grown, the model contributes to debate about how far PD care addresses the lived experiences of its patients, while providing a practical guide through which clinicians can consider PD's wider symptoms. For example, the model can identify common points of difficulty or mechanisms of change, identify common psychosocial approaches, or reduce excess disability for people with PD.

Parkinson's Disease Specialist Nurses are particularly well placed to engage with this model given their role in providing individualised psychological and social support (Hellqvist & Bertero 2015; Pedersen *et al* 2017). The role of Parkinson Disease specialist nurses includes co-ordinating the range of services used in routine PD care, assisting in the delivery of and adherence to drug treatments, and providing a central point of information and emotional support to people with PD (Bhidayasiri *et al* 2016, Theed *et al* 2016). However, research suggests that excessive workloads and wider resource demands may threaten PD nurse specialist's ability to perform this role (Reynolds et al 2000; Hellqvist & Bertero 2015). The continued expansion of PD nurse specialists should therefore be encouraged, but with sufficient allocation of resources to ensure that their roles can be delivered effectively. The model described also contributes to the development of a theoretical and practical framework for the PD nurse specialist role. This model can also influence PD care pathways by providing a structure for when and how interventions should be offered. In relation to their biopsychosocial model of dementia, Spector and Orrell (2010 pp964) conclude by stating that their model 'helps to work against (the assumption that the actions of a person are solely attributed to the illness) by taking a more individual and biopsychosocial perspective. In the context of PD, this model hopes to do the same.

Implications for Practice

- A biopsychosocial model of PD promotes a wider recognition of the environmental and social factors which affect people living with PD, and suggests ways in which health service interventions can be delivered.
- The above model illustrates how a person's needs may change as they move through the PD journey, and the dimensions in which they may need assistance and support.
- Parkinson's disease nurse specialists are well placed to deliver a biopsychosocial model of PD care, but need greater support in order to fulfil this role.

Ethical Approval. Ethical approval for the study upon which this work draws upon was given by Greater Manchester South Research Ethics Committee (MREC number 08/H1003/131).

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References

Aarsland, D., Zaccai, J., Brayne, C. (2005) A systematic review of prevalence studies of dementia in Parkinson's Disease Movement Disorders 20(10), 1255-1263. DOI: 10.1002/mds.20527

Abudi, S., Bar-Tal, Y., Ziv, L., Fish, M. (1997) Parkinson's disease symptoms-patient's perceptions Journal of Advanced Nursing 25(1), 54-59. DOI: 10.1046/j.1365-2648.1997.1997025054.x

Axelrod, L., Gage, H., Kaye, J. et al (2010) Workloads of Parkinson's specialist nurses: implications for national service guidelines in England. Journal of Clinical Nursing 19(23-24), 3575-3580. DOI: 10.1111/j.1365-272.2010.03279.x

Bartlett, R., O'Connor, D. (2010) Broadening the Dementia Debate: Towards Social Citizenship Bristol, UK: Policy Press.

Bhidayasiri, R., Boonpang, K., Jikritsadakui, O., Calne, S., Henrikson, T., Trump, S., Chaiwong, S., Susang, P., Boonrod, N., Sringean, J., van Laar, T., Drent, M., Chauduri, K. (2016) Understanding the role of the Parkinson's disease nurse specialist in the delivery of apomorphine therapy Parkinsonism and related disorders 33(1), S49-S55. DOI: http://dx.doi.org/10.1016/j.parkreldis.2016.11.014

Brown, R., Landau, S., Hindle, J., Playfer, J., Samuael, M., Wilson, K., Hurt, C., Anderson, R., Carnell, J., Dickinson, L., Gibson, G., Van Schaick, R., Sellwood, K., Thomas, B., Burn, D. (2011) Depression and Anxiety related subtypes in Parkinson's Disease Journal of Neurology, Neurosurgery and Psychiatry 82(7), 803-809. doi: 10.1136/jnnp.2010.213652

Cotrell, V., Schulz, R. (1993) The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research The Gerontologist 33, 205-211.

Department of Health (2012) Prime Minister's Challenge on Dementia. London, UK: Department of Health.

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., Robinson, L. (2016) Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews International Psychogeriatrics 29(1), 31-43. DOI: https://doi.org/10.1017/S1041610216001447

Downs, M., Clare, L., Mackenzie, J (2006) Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort In Hughes, J., Louw, S., Sabat, S. (eds) (2006) Dementia mind, meaning and the person Oxford, UK: University Press

Downs, M., Clare, L., Anderson, E. (2008) Dementia as a biopsychosocial condition: implications for practice and research. Woods, B., Clare, L. (2008) (eds) Handbook of the clinical psychology of ageing 2nd ed. Chichester, UK: John Wiley

Dixon, L., Duncan, D., Johnson, P., Kirkby, L., O'Connell, H., Taylor, H., Deane, K. (2007) Occupational Therapy for patients with Parkinson's Disease Cochrane Database of Systematic Reviews

Foster, E., Bedekar, M., Tickle-Degnen, L. (2014) Systematic review of the effectiveness of occupational therapy-related interventions for people with Parkinson's Disease American Journal of Occupational Therapy 68(1), 39-49. doi: 10.5014/ajot.2014.008706

Fox, P. (1989) From Senility to Alzheimer's Disease: the rise of the Alzheimer's Disease movement. Milbank Quarterly 67, 58-102.

Gibson, G., Mottram, P., Hindle, J. et al. (2013) Prevalence, incidence and risk factors associated with visual hallucinations in Parkinson's Disease. A four year prospective study. In International Journal of Geriatric Psychiatry . 26(6), 626-631. DOI: 10.1002/gps.3869

366 Gibson, G. (2016) Signposts on the journey; medication adherence and the lived body in men with
367 Parkinson's Disease Social Science and Medicine 152, 27-34.
368 http://dx.doi.org/10.1016/j.socscimed.2016.01.023

369 Gibson, G., Kierans, C. (2016) Ageing, masculinity and Parkinson's disease: embodied perspectives
370 Sociology of Health and Illness 152, 27-34. DOI: 10.1111/1467-9566.12508

371 Hellqvist, C., Bertero, C. (2015) Support supplied by Parkinson's Disease specialist nurses to
372 Parkinson's Disease patients and their spouses Applied Nursing Research 28(2), 86-91. doi:
373 10.1016/j.apnr.2014.12.008

374 Hurwitz, B., Jarman, B. Cook et al (2005) Scientific evaluation of community-based Parkinson' disease
375 nurse specialists on patient outcomes and health care costs. Journal of Evaluation in Clinical Practice
376 11 (2), 97-110. DOI: 10/1111/j.1365-2753.2005.00495.x

377 Kitwood, T. (1997) Dementia Reconsidered: the person comes first Buckingham, UK: Open University
378 Press

379 Kleinman, A. (1988) The illness narratives: Suffering, healing and the human condition New York:
380 Basic Books

381 Leentjens, A. (2004) Depression in Parkinson's Disease: conceptual issues and clinical challenges
382 Journal of Geriatric Psychiatry and Neurology 17(3), 120-126. DOI: 10.1177/0891988704267456

383 Matson, N. (2002) Made of stone: a view of Parkinson off periods. Psychology and Psychotherapy:
384 theory, research and practice 75(1), 93-99. DOI: 10.1348/147608302169571

385 McGill, A., Houston, S., Lee, R. (2014) Dance for Parkinson's: A new framework for research on its
386 physical, mental, emotional, and social benefits Complementary Therapies in Medicine 22(3), 426-
387 432. doi: 10.1016/j.ctim.2014.03.005

388 Mitchell, G., McGreevy, J., Carlisle, S., Frazer, P., Traynor, M., Lundy, H., Diamond, M., Agnelli, J.
389 (2016) Evaluation of 'Dementia Friends' programme for undergraduate nursing students: innovative
390 practice Dementia DOI: 10.1177/1471301216638589 Available at
391 http://journals.sagepub.com/doi/pdf/10.1177/1471301216638589

392 National Institute for Clinical Excellence. (2006) Parkinson's Disease: Diagnosis and treatment in
393 Primary and Secondary Care London, UK: NICE

394 Parkinson's Disease Foundation (2013) Parkinso's Disease Foundation.
395 http://www.pdf.org./en/parkinson_statistics

396 Parkinson's UK. (2015) Parkinson's Audit 2015 London, UK.: Parkinson's UK
397 https://www.parkinsons.org.uk/sites/default/files/audit2015_summaryreport.pdf.

398 Parkinson's UK. (2012) Parkinson's Prevalence in the United Kingdom London, UK.: Parkinson's UK
399 Available at http://www.parkinsons.org.uk/PDf/ParkinsonsprevalenceUK.PDf (last accessed
400 24/01/2012)

401 Pedersen, S., Suedmeyer, M., Liu, L., Domagk, D., Forbes, A., Bergmann, L., Onuk, K., Yegin, A., van
402 Laar, T (2017) The Role and Structure of the multidisciplinary team in the management of advanced
403 Parkinson's disease with a focus on the use of levodopa-carbidopa intestinal gel Journal of
404 Multidisciplinary Healthcare 10, 13-27. doi: 10.2147/JMDH.S111369

405 Playfer, J. (2007) Ageing and Parkinson's Disease Practical Neurology 7(1), 4-5.

406 Politis, M., Wu, K., Molloy, S., Bain, P. Chaudhuri, K., Piccini, P. (2010) Parkinson's Disease Symptoms:
407 the patient's perspective Movement Disorders 25(11), 1646-1651. doi: 10.1002/mds.23135

408 Pringsheim, T., Jette, N., Frolkis, A., Steeves, T. (2014) The prevalence of Parkinson's disease: a
409 systematic review and meta analysis *Movement Disorders* 29(13) 1583-90

Rahman, S., Griffin, H., Quinn, N. Jahanshahi, M. (2008) Quality of life in Parkinson's Disease: the relative importance of the symptoms. Movement Disorders 23(10), 1428-1434. doi: 10.1002/mds.21667

Reynolds, H., Wilson-Barnett, J., Richardson, G. (2010). Evaluation of the role of the Parkinson's disease nurse specialist International Journal of Nursing Studies 37(4), 337-349. http://doi.org/10.1016/S0020-7489(00)00013-4.

Sabat, S., Harre, R (1994) The Alzheimer's disease sufferer as a semiotic subject Philosophy, Psychiatry and Psychology 1(1), 145-160.

Sabat, S (2008) A bio-psycho-social approach to dementia. Downs, M., Bowers, B (2008) (eds) Excellence in Dementia Care: Research into Practice Maidenhead, UK: Open University Press.

Solimeo, S. (2008) With Shaking Hands; aging with Parkinson's Disease in America's Heartlands London, UK: Rutgers University Press.

Spector, A, Orrell, M. (2006) A review of the use of cognitive stimulation therapy in dementia management British Journal of Neuroscience Nursing 2(8), 381-385. DOI: http://dx.doi.org/10.12968/bjnn.2006.2.8.22035.

Spector, A., Orrell, M. (2010) Using a biopsychosocial model of dementia as a tool to guide clinical practice International Psychogeriatrics 22(6), 957-965. doi: 10.1017/S1041610210000840.

Theed, R., Eccles, F., Travers, V., Simpson, J. (2016) Anxiety and depression in individuals with Parkinson's disease: perspectives of the nurse specialist British Journal of Neuroscience Nursing 12: 3 12(3), 132-139. DOI: http://dx.doi.org/10.12968/bjnn.2016.12.3.132.

Tickle-Degnen, L., Doyle Lyons, K. (2004) Practitioners impressions of patients with Parkinson's Disease: the social ecology of the expressive mask Social Science and Medicine 58(3), 603-614. http://doi.org/10.1016/S0277-9536(03)00213-2.

Tomlinson, C., Patel, S., Meek, C., Herd, C., Clarke, C., Stowe, R., Shah, L., Sackley., C. Deane, K., Wheatlet, K., Ives, N. (2013) Physiotherapy versus placebo or no intervention in Parkinson's Disease Cochrane database of Systematic Reviews. Issue 9

Van Der Marck, M., Kalf, J., Sturkenboom, I. et al. (2009) Multidisciplinary care for patients with Parkinson's Disease Parkinsonism & Related Disorders 15 (Supplement 3), S219-S223. doi: 10.1016/S1353-8020(09)70819-3.

World Alzheimer Report (2011) World Alzheimer Report 2011; the benefits of early diagnosis and intervention Available at http://www.alz.co.uk/research/world-report-2011.

World Health Organisation (2015) Ensuring a Human Rights- Based approach for people living with dementia World Health Organisation http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf.

Wu, K., Politis, M., Piccini, P. (2009). Parkinson Disease and Impulse Control Disorders: a review of clinical features, pathophysiology and management Postgraduate Medical Journal 85, 590-595. doi: 10.1136/pgmj.2008.075820.