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

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

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

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

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

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

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

27

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

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31 **Summary Statement of implications for practice**

32 *What does this research add to existing knowledge in Gerontology?*

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

37

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

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

43

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

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

49

## 50 **Introduction**

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

## 64 ***Explanatory models; PD and Dementia***

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

75 Based in neurology, the most commonplace explanatory model for PD within medicine  
76 conceptualises the disease as the breakdown of striatal dopamine, manifested through the  
77 progressive development of motor symptomology and treated through dopaminergic and related  
78 therapies (Playfer 2007). This mono-disciplinary model has been criticized for under-recognising and  
79 under-treating much of PD's symptomology (Van Der Marck et al 2009; Gibson 2016). Greater  
80 attention is now being paid to PD's non-motor symptomology within routine care, inclusive of  
81 symptoms such as dementia (Aarsland et al 2005), mood disorders (Leentjens 2004), hallucinations  
82 (Gibson et al 2013), impulse control disorders (Wu et al 2009), or the side effects of dopaminergic  
83 therapies (Matson 2002). Questions have also been raised regarding the relative impacts of PD's  
84 symptoms on quality of life, with research showing that PD patient's complaints diverge significantly  
85 when compared to those symptoms prioritised in PD's routine therapy (Tickle-Degnen & Doyle Lyons  
86 2004). For example, while patients highlight mental, functional and psychosocial impairments as  
87 their biggest problems, clinicians routinely judge motor symptoms which respond to anti-Parkinson's  
88 drugs as most distressing (Abudi et al 1997, Rahman et al 2008, Politis et al 2010). Although useful  
89 for identifying and addressing disease pathology, PD's conceptualisation within medicine therefore  
90 differs greatly when compared to patient's judgements about PD, leading to significant differences  
91 between clinical priorities and patients lived experiences.

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

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

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

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

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

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

139 ***Dementia; a biopsychosocial model***

140 FIG 1 HERE

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



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

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

162

### 163 ***A bio-psycho-social model of PD***

164 FIG 2 HERE

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

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

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

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

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

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

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

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

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

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

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

## 264 **Conclusion**

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

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

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

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

### 310 ***Implications for Practice***

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

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

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