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1 **Title: *Ageing, masculinity and Parkinson's Disease: Embodied perspectives***

2

3 ***Abstract***

4 Parkinson's Disease (PD) presents as an illness which predominantly affects older men. However older  
5 men's lived experiences of PD, including how they are influenced by age and gender relations has seen  
6 little empirical study. Drawing on Watson's (2000) male body schema, this paper explores PD's effects  
7 on men's bodies, alongside how men engage with masculinities and ageing in order to make meaning  
8 from these experiences. Data is presented from 30 narrative and semi structured interviews with 15  
9 men of various ages who were living with PD. Findings suggest that PD threatens a pragmatic  
10 embodiment expressed through men's everyday occupations; a visceral embodiment located in  
11 difficulties with the body's basic movements and intimate functions and an experiential embodiment  
12 concerned with emotions and sensations within and about the body. In addition, each dimension of  
13 men's embodiment also intersected with the ageing process, a process also shaped in turn by broader  
14 social and cultural concerns regarding the positions and possibilities of men's lives as they move  
15 through the life course. This paper concludes by discussing the implications of gender and ageing in  
16 understanding men's experiences of PD

17 ***Keywords***

18 Parkinson's Disease. Embodiment. Masculinity. Ageing

19 Word Count.

20

21

## 22 **Introduction**

23 Historically classified as a movement disorder, Parkinson's disease (PD); a chronic, progressive  
24 neurological condition whose major symptoms (muscular rigidity, tremor and akinesia) affect  
25 movement and mobility is increasingly being recognised as an illness affecting the totality of a person's  
26 life (Jankovic 2008). Yet despite an increasing focus within clinical research on PD's non-motor  
27 symptoms, including depression, anxiety, hallucinations and the side effects of PD therapies, PD's  
28 routine care remains focused on alleviating motor symptomology through drugs (Playfer 2007;  
29 Parkinson's UK 2011). Exacerbating this trend, clinical research in PD has largely failed to engage with  
30 PD's lived experience, as demonstrated in the divergence between the condition's clinical priorities  
31 and patients own concerns (Abudi *et al* 1997; Bramley & Eatough 2005; Solimeo 2008; Stanley  
32 Hermanns & Engbretson 2010). Although having much to offer, sociological approaches exploring  
33 chronic illnesses as situated within social practices have not yet critically engaged with PD. As a  
34 consequence, our knowledge of PD as a lived condition embedded within the social world has been  
35 under-explored (Solimeo 2009).

36 Age and gender relations have particular salience in PD. PD has been indexed to the process of ageing.  
37 With an age of onset of typically around 60 years, advancing age is the only risk factor consistently  
38 associated with the disease (Hindle 2010). In addition, prevalence studies suggest that PD affects 1.5  
39 to 2 men for every woman; men also report worse symptoms and poorer quality of life (De Lau &  
40 Breteler 2006; Haaxma *et al* 2007). PD's symptomology has been described using sex or age based  
41 epidemiological differences (Haaxma *et al* 2007) or via biological problems distinct to the sexes, such  
42 as menstruation or erectile dysfunction (Meco *et al* 2008). Yet despite organising much of PD's  
43 symptomology, the impact of age and gender relations in PD have thus far been neglected (Solimeo  
44 2008; Davidson & Meadows 2010). PD therefore gives us an opportunity to explore how age and  
45 gender intersect in the context of chronic illness (Hearn 2009; Solimeo 2009; Calasanti 2010).

46 Embodied perspectives, concerned with the lived body and its experience in disease-states, provide  
47 an important route to elaborating the role age and gender relations play in informing chronic illness  
48 experiences (Merleau Ponty 1962; Leder 1990; Toombs 2002). Yet it is only relatively recently that  
49 men's embodiment in relation to health has been subject to critical enquiry (Courtenay 2000;  
50 Robertson 2006). Watson's 'male body schema' (2000), further developed by Robertson (2006; 2007;  
51 Robertson *et al* 2010) has been advanced as a useful starting point. In the male body schema, a  
52 normative embodiment or the idealised experience of the male body is constituted by three inter-  
53 related embodied dimensions; a visceral embodiment or the physiological processes constituting the  
54 male body, a pragmatic embodiment defined by men's bodily capacity to complete everyday tasks  
55 and an experiential embodiment reflecting the vividness of bodily sensations. These distinctions are  
56 not mutually exclusive, instead they interact with each other to shape the ways in which men inhabit  
57 their bodies, doing so at different times and in different contexts (Robertson *et al* 2010).

58 Although men's' embodiment is now growing as an area of research, the study of masculinities as men  
59 age remains in its infancy (Thompson 2007; Calasanti 2010; Tarrant 2014). Originating within feminist  
60 gerontology, a limited body of work has proceeded by theorising gender and age relations as  
61 intersecting processes (Calasanti 2005; Krekula 2007; King & Calasanti 2013; Tarrant 2014). Studies  
62 have explored commonalities of experience in men's ageing such as grandfatherhood (Scraton &  
63 Holland 2006), widowhood (Bennett 2007) and the provision of spousal care (Russell 2007). Yet the  
64 embodiment of gender and ageing within chronic illness experiences remains under-studied (McVittie  
65 & Willock 2006; Hurd Clarke & Bennett 2013). The consequences of illness are as much linked to the  
66 wider cultural processes and discourses attached to bodies as they are to visceral changes, meaning  
67 both physiological changes and social practices together inform our understandings of men's  
68 embodiment as they age (Calasanti 2005; Solimeo 2009). A small body of work has explored the  
69 importance of gender and age relations in PD. Solimeo (2008) has illustrated how, despite  
70 experiencing similar symptom profiles and effects on quality of life, men and women's lived

71 experiences of PD occupy differing gendered standpoints. Specifically women's accounts of PD were  
72 situated within their domestic responsibilities and a collective, family identity. In contrast, men  
73 focused on the body's functionality and declines in traditional male roles leading to men's withdrawal  
74 from social relationships. PD can also be situated within cultural patterns of ageing. Describing PD  
75 as 'premature social ageing', Singer (1974) describes how PD is understood through social  
76 expectations of bodily decline conventionally associated with an older age, but in this case, felt far  
77 earlier in the lifecourse than ordinarily expected. Solimeo (2009) also draws out tensions when using  
78 discourses of ageing to account for PD's lived experience, with PD both accelerating the physiological  
79 experience of ageing while also obscuring the natural ageing process, creating confusion regarding the  
80 boundaries between PD pathology and typical bodily ageing. Such studies therefore demonstrate the  
81 importance of exploring gender and age relations and their intersection in PD.

82 Building on the literature in men's health and the nascent study of ageing masculinities, this paper  
83 explores men's experiences of PD in terms of a masculine, ageing embodiment. Drawing on visceral,  
84 pragmatic and experiential dimensions of the male body schema, this paper discusses how PD is  
85 experienced in relation to a masculine embodiment, which in turn intersects with cultural discourses  
86 and expectations relating to ageing. In doing so, this paper contributes to the development of theory  
87 regarding masculinity, ageing and health.

## 88 **Methods**

89 This paper reports findings from a project exploring men's experiences of living with PD (ANONYMISED  
90 REF 2013). Thirty interviews were carried out with 15 men in 2011-2012. Participants were identified  
91 from a sub-sample of 100 men taking part in a clinical study investigating mood disorders in PD  
92 (ANONYMISED REF 2011). Participants attended outpatient PD, geriatric and movement disorder  
93 clinics in North West England and North Wales. A maximum diversity sampling approach drew on  
94 clinical research data to capture as wide a range of PD symptomology as possible, without reliance on  
95 a convenience sample. The sample was stratified according to age, PD severity, PD duration, and

96 presence of motor and non-motor symptoms (table 1). Ethical approval was given by NHS South  
 97 Manchester Research Ethics Committee (MREC number ANONYMISED).

Pseudonym	Age	PD Severity (Hoehn & Yahr* 1-5)	PD Duration (years)	PD Motor symptoms (UPDRS**)	PD Non motor symptoms (GMS***, self-report)
Bob	80	3	13	Tremor, rigidity, postural instability, slowness	Depression
Simon	53	1	4	Tremor, rigidity	None
Henry	77	3	13	Tremor, Rigidity, postural instability, slowness,	Impulse control disorder. Incontinence
Tony	62	2	7	Tremor, Slowness	Anxiety, depression
Harold	80	2	4	Slowness, rigidity	None
Tom	83	4	11	Tremor, slowness, rigidity, postural instability	Impulse control disorder
David	71	2	9	Rigidity, slowness,	None
Ian	76	2	6	Tremor, rigidity, slowness, postural instability	depression
Dafydd	73	2	15	Tremor, rigidity, slowness, postural instability	Hallucinations
John	66	2	3	Rigidity, slowness	None
Phillip	76	4	11	Rigidity, postural instability, slowness	None
Hugh	67	3	11	Tremor, rigidity, postural instability, slowness	Anxiety, Depression, Impulse control disorder. Hallucinations
Peter	76	2	3	Tremor, slowness, rigidity	None
Albert	69	3	5	Tremor, rigidity, postural instability, slowness	Anxiety, depression. Impulse control disorder. Incontinence
Roger	55	3	13	Tremor, rigidity, postural instability, slowness	Anxiety, depression, Impulse control disorder. Hallucinations. incontinence

**Table 1 Interview participants**  
 \* Hoehn & Yahr Rating Scale (Hoehn & Yahr 1967) PD graded in severity on scale of 1 (unilateral disease, minimal disability) to 5 (severe disability - bedridden or wheelchair bound)  
 \*\* Unified Parkinson's Disease Rating Scale (Fahn *et al* 1987)  
 \*\*\* Geriatric Mental State Examination (Copeland *et al* 2002)

98

99 The average age of the sample was 71 (range 53-83). The majority of the men were in older age,  
 100 defined here as being over the age of retirement. In addition three were aged 80 or over. Four of the  
 101 men were in middle age, defined here as the ages between 45 and 65, with all four men being in their  
 102 fifties or sixties. Two men were still in employment; the rest had retired or left work due to ill health.  
 103 Six had been employed in manual or skilled technical occupations, while nine were middle class  
 104 professionals. All of the men in this sample self defined as heterosexual.

105 The study adopted a phenomenological approach using narrative methods (Mishler 1986; Riessman  
106 1993). Drawing on Wengraf's (2001) biographical narrative interview methodology each man took  
107 part in an initial narrative interview followed by a semi-structured interview which further investigated  
108 narrative themes. Interviews lasted 1-4 hours and were conducted by the first author. Follow up  
109 interviews took place 1-3 months later after an initial analysis of narrative interviews. Interviews were  
110 audio recorded and transcribed verbatim by the first author. All participants were given the  
111 opportunity to comment on their transcripts, with two men doing so. Analysis was carried out by the  
112 first author with regular discussion with the second author. Taking as a starting point the idea that PD  
113 disrupts a normative 'taken-for-granted or 'absent' embodiment (Leder 1990), the study explored  
114 men's stories about living with PD and how gender and ageing were 'emplotted' within these stories  
115 (Mattingly 1998). Narratives were organised into themes using Watson's (2000) male body schema.  
116 Transcripts were separated into individual stories relating to a specific activity or experience. These  
117 stories were then organised into themes such as, occupations, bodily sensations, emotions and  
118 moods. Themes were then organised in relation to pragmatic, visceral and experiential dimensions of  
119 embodiment. Findings are discussed in three sections. First we explore PD's implications for a visceral  
120 embodiment which in turn are influenced by expectations of men's ageing. We then discuss a  
121 pragmatic embodiment, in which men drew on masculine occupations to comprehend PD's losses and  
122 reassert a masculine identity. Finally we discuss an experiential embodiment, where the emotions  
123 and sensations attached to PD's symptoms led to the experience of a fluctuating bodily state which in  
124 turn threatened the accomplishment of masculinity.

125

## 126 **Results**

### 127 ***PD and a visceral embodiment***

128 A visceral embodiment refers to the underlying biological and physiological processes supporting the  
129 'real' physical body (Robertson 2006). Most commonly, men began their accounts of PD with its  
130 effects on the body's physical ability to move;

131 *Bob. I don't know if I can blame Parkinson's for my walking. If it is Parkinson's that's*  
132 *causing my walking, then it has affected me, and it is affecting me more. And balance as*  
133 *well. It's as if I am carrying one tonne shoes. Yeah. It's just, I'm walking, you know, zig*  
134 *zagging, I feel that, and I don't think that that is just old age.*

135 Difficulties with movement were also expressed in terms of losing stamina, fatiguing easily, or  
136 generally feeling shaky, heavy or slow. When describing these experiences, men frequently  
137 referenced the physiological declines expected in older age. When asked about his difficulties with  
138 walking Harold claimed '*well I am eighty you know*'. Yet although most felt some slowing was to be  
139 expected as men aged, they also felt their experiences could not be put down to '*just old age*'. Peter  
140 also compared his slowing to other people of similar ages;

141 *Peter: It's annoying, I'm walking along, and I see people, this little old lady, and I say*  
142 *to myself, they're walking slowly, but they're overtaking me, and the next thing I think*  
143 *I'm slower than them (laughs). They're walking slowly, so I must be walking even more*  
144 *slowly. And I used to be able to stride away. (...) Its just this old chap shuffling along,*  
145 *that's me. I expected to be slow, but not this slow.*

146 Men in middle age also drew on expectations of bodily ageing when describing many of their  
147 difficulties. Aged 53, Simon described the difficulties he faced when crossing a road;

148 *Simon When I'm in town I'll stop at the village, in the road, and I'll look, and I'll look,*  
149 *and I'll look again. Because you know that when you walk across the road sometimes you*  
150 *don't walk as quickly as you want to, and you can't actually make yourself hurry, so you*  
151 *make sure it's safe to cross. Whereas I suppose if I was a typical elderly person, I would*

152           *just cross slowly and people would have to pull to a halt while I carried on crossing*  
153           *obliviously. So that's me saying, it's ageing me in that respect.*

154   Instead of just striding out, Simon now had to be more cautious, taking more time to cross. Such  
155   problems might be expected later in life but not at 53, leaving Simon feeling prematurely 'old'. Men  
156   could explain the physiological changes they were facing in PD through expectations of a normalised  
157   bodily ageing. However, and occurring at different times depending on their illness, the slowing and  
158   other physiological changes occurring in PD eventually came to be experienced as something over and  
159   above 'normal' ageing; as men slowed or faced difficulties not expected till much later in life, or as  
160   they became slower than people of similar ages.

161   PD also affected a number of the visceral body's most intimate bodily functions, with problems  
162   associated with drooling, incontinence and sexual dysfunction being described as acute threats to  
163   masculinity (Chapple & Ziebland 2002). Roger, aged 55 explicitly linked incontinence to the loss of a  
164   masculine self image;

165           *Roger.   Getting to the toilet in time. You know, it's a simple thing but it erodes your*  
166           *masculinity a little bit doesn't it. You know. So why I wear white trousers I dunno. Simple*  
167           *things like that, if you happen to be weak, it takes a hell of a lot of bladder control. I can*  
168           *just about make it, but sometimes you fail. It doesn't do anything for your masculinity does*  
169           *it.*

170           Roger

171   A common problem in PD, incontinence required intimate bodily management. Men frequently  
172   reported having to avoid any public spaces lacking public toilets, be watchful for the bodily sensations  
173   indicating the need to urinate/defecate, wear incontinence pads or return home should incontinence  
174   occur. Several men recalled episodes where they had been incontinent in public. Henry described an  
175   incidence of incontinence when buying a car far from home.

176           Henry     *I went to get out of the car and I was soaking wet. Absolutely soaking wet, my*  
177           *bladder had let loose (...). So now I'm in a position I'm soaking wet, I'm a long way from*  
178           *home, I'm fed up, so do I go home or what. So I rang them and I said "look I'll tell you*  
179           *straight now, I've got Parkinson's disease, I've just had a mishap in as much as my*  
180           *bladder's just let go, I'm soaking wet, if you don't want to see me I quite understand, but*  
181           *I can't come back all this way again, so it's now or never sort of thing". (...) I can honestly*  
182           *say coming away from there they were very friendly people, (...) there were three men*  
183           *there that I was dealing with, two of them had got experience of Parkinson's in the family,*  
184           *and they wanted to know more.*

185   Such stories demonstrated the difficulties arising from incontinence, but also showed ways through  
186   whih stories could be used to keep a masculine self image intact. Roger felt it was that it was  
187   unacceptable for a man to be seen to be incontinent, in particular worrying about the visibility of his  
188   body in public space;

189   *Roger: God forbid if I have white trousers on and I go for a piss, and spill a bit stuff like that, so, and if*  
190   *I'm fidgety, you think everybody sees it, you know. I think everybody's looking at me, cos I know they*  
191   *are.*

192   In contrast, , Henry preferred to 'be up front' about his incontinence when it occurred in public. For  
193   both Henry and Roger, incontinence was also mediated expectations of their bodies given their ages.  
194   For Henry, attributing incontinence to his PD was preferable to its association with older age.. Indeed  
195   Henry claimed telling people that incontinence was a symptom of PD elicited a more sympathetic  
196   response, legitimising his experience as part of a disease process.

197

198 In contrast, Roger could not associate his incontinence on more conventional expectations of bodily  
199 ageing, For men such as Roger, illness could be used to explain their symptoms, however  
200 embarrassment or shame could continue to be felt even after such episodes. For Roger, his middle age  
201 meant ageing was not available as a means to explain his symptoms, while, explaining his incontinence  
202 as part of his illness still failed to account for the embarrassment or shame he felt. As a result, younger  
203 men were more likely to describe incontinence as a threat to their masculine status.

204 Problems with sexual function in PD also posed problems for masculine identities, with these problems  
205 also being mediated by age. Further complicating the experience of sex in PD, changes in sexual  
206 function could be due to the disease or alternatively could result from its treatment, presenting as  
207 either erectile dysfunction or hypersexuality; what several men described as abnormal or worrying  
208 changes in sexual desire (Merims & Giladi 2008). Loss of sexual function was initially understood as  
209 something expected in old age and therefore largely irrelevant to older men's lives, its loss something  
210 to be dismissed or joked about. If older men talked about difficulties with sexual function they  
211 commonly made a joke of it, for example claiming they were '*a bit old for that*' (Harold) or '*a bit long*  
212 *in the tooth for that sort of thing*' (Henry). Peter thought erectile dysfunction posed greater problems  
213 for 'pissing' than sex;

214 *Peter: Severe erectile dysfunction, which is, I can't even pee properly now, I have to*  
215 *drag myself out, which is very annoying, yeah.*

216 *Int Does erectile dysfunction impact other aspects of your life?*

217 *Peter. No, I mean I don't have sexual intercourse, that sort of thing. Well apart from*  
218 *going out and buying some Viagra do you mean! (laughs).*

219 Yet a number of older men described still having masculine desires, in many cases describing them as  
220 a natural part of their masculinity. Albert claimed he still had a libido, describing himself as being '*a*  
221 *bit naughty*';

222 *Albert well I do have a libido still. Most people do, even though they might not be able to*  
223 *perform, either with advancing age or advancing Parkinson's disease, the ability to*  
224 *perform decreases, but libido does not necessarily decrease. It doesn't mean that you can*  
225 *actually do anything, raise to an err, you know, could have unfortunate consequences like*  
226 *fathering an unwanted child. You can't do anything dramatic, but you may feel a little bit*  
227 *turned on, and be a bit naughty in the way you talk to people or, err, flirt with them for*  
228 *example.*

229 Later in the interview Albert revealed he had started watching pornography, a new experience which  
230 he described both as a natural masculine desire and as something to be scornful of;

231 *Int. You mentioned that you'd been viewing pornography.*

232 *Albert. Yeah. I mean is there any man who doesn't occasionally. I don't anymore*  
233 *because it's rather boring.*

234 *Int. Was that relatively recently?*

235 *Albert. It's a substitute for the actual thing isn't it.*

236 *Int. Is it recently you were doing that?*

237 *Albert. Yes. I used to be scornful of it; it's an old man's hobby isn't it. So called adult*  
238 *films, I watched them three or four times, and my wife found out from the bank*  
239 *statements and told me in no uncertain terms to stop it, so I did.*

240 Albert's wife prescribed very different meanings to this behaviour, describing his increasing libido as a  
241 distressing and out of character change in his behaviour she had raised with his doctors – a potential  
242 form of hypersexuality. The acts and feeling associated with sex could be understood as an expression  
243 of a stereotypical heterosexual masculinity, something lost naturally as men aged, an '*old man's*  
244 *hobby*', no longer appropriate in older age and therefore worthy of scorn, a deviant behaviour  
245 potentially distressing for the individual and those around them or finally a part of their illness to be  
246 monitored and treated.

247 In contrast men in middle age were more likely to describe sexual difficulties as an overt threat to their  
248 masculine status. Roger also worried about his declining libido;

249 *Roger (...) I suppose from the sex point of view I suppose, I find that you're losing, what's*  
250 *the word, libido is it. Losing a little bit of that. It bothers me from time to time when I want*  
251 *sex. I don't dwell over it, I think she's satisfied, well I am. But I don't know. Yeah. I think*  
252 *we're happy.*

253 Roger expressed doubt about whether he could 'satisfy' his wife sexually, later leading him to question  
254 whether he was 'a real man'. The difficulties with sexual function associated with PD also went beyond  
255 the physical act of sex to threaten the continuation of a masculine self fully able to participate in the  
256 wider aspects of human sexuality, such as men's sense of being a sexually attractive being. In middle  
257 age but recently widowed, Simon hoped to meet another partner, viewing himself as a bachelor rather  
258 than a widower. However Simon feared his PD would prevent another partner committing to a  
259 relationship with him, making him '*damaged property*':

260 *Simon. I lost my wife in July, but I would like to at some point meet another partner. I'd*  
261 *like to think that if I've got another twenty years on this planet I don't want to do it alone.*  
262 *(...) but owning up to Parkinson's is going to be the kiss of death to any relationship. I*  
263 *question whether I'm actually, what's the word. I suppose tarnished goods is probably the*  
264 *best expression. Damaged property.*

265 Unwilling to resign himself to widowhood, Simon also worried if he would be able to attract another  
266 partner. Simon and Roger more closely aligned their difficulties with what they expected to be  
267 experienced by men 20-30 years their senior, both in terms of sex and more widely regarding their use  
268 of the physical body;

269           *Simon: many other people in my situation are seventy, seventy five or older, got arthritic*  
270           *fingers or have too bad the tremor to deal with it. It must be hell. And I think what's it*  
271           *going to be like for me in those days, when its hell for me now.*

272           For men in middle age PD and its symptoms could therefore threaten a continuing masculine identity  
273           based the control of the intimate bodily functions. Men's accounts were particularly associated with  
274           incontinence or sex and the continuation of a sexual masculine self, with men drawing on their  
275           experiences and expectations of bodily changes across the lifecourse to explain the physiological  
276           changes occurring in their bodies, doing so in different ways according to both their ages and their  
277           individual constellation of symptoms.

#### 278           ***PD and a pragmatic masculine embodiment***

279           A pragmatic masculine embodiment is concerned with the use of the body as a resource for the  
280           completion of physical, masculine activities and the gender roles through which they are sustained  
281           (Connell 1995; Watson 2000; Robertson 2006; Wiersma & Chesser 2011). Alongside the physiological  
282           effects, PD's symptoms came to be known through their effects on the body's ability to complete a  
283           range of stereotypically masculine forms of labour, work or leisure and the biographies and identities  
284           expressed through them. Tony described PD's effects in terms of his ability to accomplish '*heavy*  
285           *work*';

286           *Tony. Err, just, I haven't the energy to do heavy work. Gardening, or working on the*  
287           *car. If there's digging I can only do it for about half an hour and then I come in and I do*  
288           *whatever I'm doing, have a read or whatever, and if I feel like it I go out and do a bit more.*  
289           *But I mean I've managed to do some quite heavy things. Once I get going, I'm not too bad,*  
290           *but it depends on the day.*

291 Men's accounts of PD frequently focused on its consequences for men's work, defined through tasks  
292 including DIY or gardening, skilled technical work such as car maintenance, electrical rewiring or  
293 plumbing, or sports and hobbies like golf, bowls or rambling. Lacking strength and stamina, tasks such  
294 as lifting, carrying or digging became more difficult. Tremor restricted dextrous, skilful or detailed  
295 work, while fatigue left men struggling to keep up in their activities with other men. But importantly,  
296 when describing their difficulties men also tried to show what they could still do;

297 *Dafydd. it was wiring a plug, that's the simplest thing in the world, wiring a plug. But*  
298 *because of the way I couldn't grip properly, I had to find all sorts of ways of manipulating*  
299 *the screwdriver, very frustrating. Over the years I think I improved, I can still put a wire in*  
300 *a plug, purely and simply because of what I've learnt. What I've learnt is that the body,*  
301 *and the brain, can be trained to organize a job, to do it in a different way.*

302 Dafydd could find new ways to use his body in order to complete his tasks. In contrast Tony tried to  
303 stoically carry on with 'heavy things' despite their difficulty, promoting his successes when doing so.  
304 By telling such stories, men could show how they overcame the limitations of their PD, keeping familiar  
305 elements of a biographical identity intact while also maintaining a masculinity based on physical  
306 activities and abilities (Emslie *et al* 2006).

307 Despite trying to show what they could still do, PD's progressive character meant that men inevitably  
308 faced increasing difficulties with their different tasks and actions. Yet men still tried to account for  
309 losses in ways which preserved a masculine identity. As more strenuous leisure pursuits were lost,  
310 John, David, Phillip and Harold took up less demanding activities such as bowls, croquet or snooker,  
311 using less strenuous activities to express themselves and their place in the world;

312 *John But I'm now giving golf up. My next move is to crown green bowls, cos (wife)*  
313 *wants to play that, so I shall play it.*

314 *GG So as you have to give up some things...*

315           John.     *I'll move on to the next.*

316     However as PD's symptoms continued to worsen time, it inevitably became harder for men to sustain  
317     their efforts. Attempts to do things in new ways often failed, while less demanding hobbies became  
318     too tiring or difficult. to continue with. For some, the loss of physical activity eventually threatened  
319     their biographical identity: who they considered themselves to be. Ian, a retired carpenter grew upset  
320     as he spoke about losing abilities associated with his trade:

321           Ian.       *(becomes tearful). But it's the physical demand of doing things that I can't cope*  
322           *with. Things that you wouldn't give a second thought to when you were fit, but now I have*  
323           *to think, how can I get round this, and how can I get round the other, and how can I do*  
324           *this, and how can I do that, I've got to be thinking all the time, to work out solutions, and*  
325           *I tried putting a bell on the front door, that's as far as I got, it won't work. I've had it on*  
326           *and off and on and off and on and off and I can't get it to work at all.*

327     For Ian, fitting a doorbell was something he felt he should easily be able to accomplish no matter his  
328     age. While older men could again blame some loss of activities on the natural declines of ageing,  
329     younger men still expected to be much more active. Alternatively men could find themselves  
330     struggling with occupations which they felt they should be able to accomplish regardless of age, either  
331     because of their perceived simplicity, or because of their attachment to men's biography.

332     The body's ability to carry out activities associated with a pragmatic masculine embodiment were  
333     therefore a key means through which men understood PD and its effects. Through their actions and  
334     practices, men could continue to assert a masculine identity by showing either stoicism or the ability  
335     to adapt and change. However PD's worsening symptoms meant these stories were also subject to  
336     change, eventually failing for many men. In such cases if both a pragmatic embodiment and a  
337     biographical identity were to remain intact, men needed to find new stories to tell about their  
338     condition. By challenging men's ability to carry out tasks central to both individual identities and

339 idealised forms of masculinity, PD threatened a pragmatic embodiment defined through men's  
340 labours.

### 341 ***PD and an experiential embodiment***

342 Experiential embodiment concerns the sensations felt within the body, the emotions felt through the  
343 body, and feelings attributed to the body as it interacts with the various objects, activities and people  
344 in the world (Robertson 2006). Changes in visceral and pragmatic embodiments were also  
345 accompanied by changes in an experiential embodiment. Alongside its physiological symptoms,  
346 bodies in PD no longer felt 'sharp' i.e. having the capacity to respond quickly to the world around  
347 them. Arms and legs were no longer able to move quickly and effortlessly, instead feeling laboured  
348 and heavy, what Bob has previously called '*wearing one tonne shoes*'. Men with PD also described  
349 adopting a new attunement to or way of thinking about the body. Peter described having to verbally  
350 tell his body how and when to move:

351 *Peter. When we have drinks she can't carry them, so I carry them in, and what I find*  
352 *interesting, whenever I'm holding something. Now I used to just let go, but sometimes he*  
353 *doesn't let go, I have to say 'let go hand', so to speak. (...) It's definitely different.*

354 The body itself increasingly had to be thought about, instructed and managed. Peter found himself  
355 having to pay attention to his hand as it picked up a cup, rather than to the cup itself. Rather than  
356 simply and unconsciously interacting with the various objects in the world, men increasingly had to  
357 think about the body, requiring both thought and concentration if they were to use it in the manner  
358 they wanted to. For many men, the body increasingly presented itself to their consciousness as an  
359 object, in many cases explicitly separate to themselves. Thoughts and memories were also affected,  
360 making men feel increasingly out of place as memories were forgotten or took longer to be recalled,  
361 or as conversations needed greater concentration and effort. Hugh struggled to keep up social contact  
362 with his family or friends:

363        *Hugh: You are in conversation with somebody, and all of a sudden you've forgotten the*  
364        *name completely. It could be somebody well known, who you've worked with, and you just*  
365        *can't. I go through the alphabet sometimes trying to memorise names. (...) It's*  
366        *unpredictable, if you start a conversation and half way through, 'oh what's he talking*  
367        *about', it's gone from your mind. It happens quite often, especially when you are in*  
368        *company. It's embarrassing that.*

369 men's experiential embodiment were also closely related to the experience of taking PD's various  
370 medications. Rather than returning bodies to the taken-for-granted, absent status of good health, PD's  
371 various medications could be 'felt' to work, with a range of both positive and negative consequences  
372 for the felt body. Alongside improving physical functioning, the sudden influx of artificial dopamine in  
373 the brain upon taking a tablet was accompanied by often vivid bodily sensations:

374        *David. When they kick in, you feel as if a weight comes off your body, and you feel, ahh,*  
375        *I can move. But it isn't a weight, it's like a restriction, and it frees itself, gradually, and all*  
376        *of a sudden you find you can move your legs much more easily, and you can walk more*  
377        *naturally. It comes on very quickly, but then it dies down slowly after that. (...) If I keep*  
378        *taking my tablet at the right time, it keeps me going.*

379 Men frequently described experiencing sudden changes in body sensations after taking medications,  
380 what Hugh described as '*returning back to the planet*' or David called '*kicking in*'. During these periods,  
381 what have been called 'on' states within PD's routine therapy, PD's physical symptoms subsided; for  
382 example tremor could disappear while muscular stiffness also reduced, allowing the body to move  
383 more freely (Matson 2002). These physical benefits were also accompanied by other sensations. The  
384 body seemed to relax, for example being described as losing a heavy weight or feeling '*good*' or '*free*'.  
385 Several men described feeling a 'boost', in which they moved and felt much quicker than before. On  
386 states were usually pleasant, but as PD progressed, larger doses were required in order to gain the

387 same therapeutic benefit. As PD worsened and the doses needed to promote an on state grew bodies  
388 also began to move 'too much'; exemplified by by dyskinesia's or tics, jerks and other involuntary  
389 movements. Alongside dyskinesia, during on states a few men also described , what Hugh called  
390 feeling 'hyperactive';

391 *Hugh. You're hyperactive then. You just want to do things, and get things and do things*  
392 *that don't really need doing. You see something that's broken down, you want to repair it*  
393 *that minute, you can't leave it till the next day.*

394 Men could feel 'driven', 'buzzing' or 'wired' during on states, sensations which could also be  
395 accompanied by a number of impulsive drives or desires; described by Henry as 'doing too much';

396 *Henry; (consultant) and my wife got their heads together and my wife's theory was that*  
397 *my Parkinson's was being aggravated by the very fact that I was doing too much. One of*  
398 *the things I was doing was buying and selling cars, which I used to earn a living at. At a*  
399 *time when I should have been retired and relaxing, I was going out and buying two or three*  
400 *cars in a day and putting them on sale and moving them around garages. She mentioned*  
401 *it to (consultant), and he said, 'well why are you doing it if you don't mean to do it'. 'I don't*  
402 *know really, I've got to keep going like', and he thinks that its related to the compulsive*  
403 *behaviour that some people get, the gambling, some get it with sex, some get it with*  
404 *shopping or what have you.*

405 Other men faced similar problems; Tom found himself 'flittering', unable to focus on any one thing  
406 and struggling to complete his daily tasks. Henry and Roger wanted to spend money unnecessarily  
407 while Hugh had gambled profusely, losing large amounts of money. For several men these experiences  
408 were distressing, leading them to seek assistance from their medical practitioners. Yet in practice  
409 beyond reducing the frequency or strength of medications there was little the medical staff treating  
410 them could do to assist them with these problems. In such cases men either had to put up with them

411 using what Hugh called '*mind over matter*' or reduce their medication dosages, potentially reducing  
412 such experiences occurring but at the same time worsening their motor symptoms.

413 Several men also experienced 'wearing off', periods during which medications lost their efficacy and  
414 PD's symptoms returned. David described what wearing off felt like;

415 *David. Oh, hopeless. Well imagine holding a potato, and peeling it, and you haven't got*  
416 *any strength to press the peeler against the potato. Everything slows down. And you*  
417 *sometimes feel your feet are like lead weights, they're there, but they seem to stick to the*  
418 *floor.*

419 When wearing off, bodies seemed to suddenly slow down, once again feeling heavy or empty of  
420 energy. Wearing off could be solved by r taking medications earlier than prescribed or overdosing; a  
421 risky strategy which could have repercussions for their bodies for the rest of the day. As PD advanced  
422 wearing off also developed into 'off periods'. The opposite of on states, during off periods  
423 medications suddenly lost their efficacy. Seemingly unrelated to the timing of their medications, off  
424 periods could be predicted or alternatively could happen at any time of day(Matson 2002). During  
425 off periods Hugh felt '*like a zombie*';

426 *Hugh. It just comes on like a light switch. One minute you'll be fine, the next minute*  
427 *you're like a zombie. And my partner notices it straight away. She's only got to look at me,*  
428 *she can tell. They feel terrible to be honest. (...) When you are in an off period you feel so*  
429 *lowsy it's unbelievable. Your co-ordination, you're like, you are stiff more or less, you can't*  
430 *get going properly. So you just wait for (medication) to kick in and then get back going*  
431 *again.*

432 In off periods bodies suddenly felt heavy, empty of energy and unable to fulfil simple tasks. Almost all  
433 movement ceased, while thinking slowed to a crawl. Once started all Hugh could do was wait out an

434 off period, taking a 'booster' medication in the hope of speeding its passing. For those experiencing  
435 them life increasingly had to be planned around off states, for example men curtailing any activities if  
436 they felt the tell-tale sensations indicating the start of an off period.

437 Finally, the emotions attached to PD and its symptoms often left men struggling to perform and  
438 accomplish routine, normal everyday tasks, that they regularly associated with their identities as men..  
439 Roger ran a building company, spending lots of time on the site with other men. Enacting a form of  
440 masculinity, valorising a strong physical presence, and engaging in jocular and at times aggressive  
441 'banter', was a common feature of his working life. Now felt he had to 'put up a front' at odds with his  
442 actual bodily state;

443 *Roger In the old days these sort of problems (on the building site), fucking hell I can*  
444 *deal with that Wednesday afternoon, no problem. I'm so conscious of that, that I'm half*  
445 *the man I was. That's not nice (...) it's a front I have to put up, erm, it's a real front because,*  
446 *you know, if people think you are weak they'll take advantage of you. That's what I've*  
447 *found (...) you know it would be nice to be able to go any time you like, rather than having*  
448 *to psych yourself up or something, yeah*

449 For Roger, masculinity became an increasingly visible performance as he struggled to 'pass himself  
450 off' as the person he once was. The significance of an experiential embodiment in PD lay in its  
451 increasingly fluctuating bodily experience. PD's symptoms led to numerous, changes in the body while,  
452 PD's drug therapy, although bringing numerous benefits in practice themselves led to men  
453 experiencing a balancing act between visceral and sensory embodiments. Together these experiences  
454 posed continued challenges to the experience of a taken for granted, habitual masculine body.  
455 Whether pleasant or detrimental the experiences associated with fluctuations between 'on' and 'off  
456 states' each distanced men from the taken-for-grantedness of embodied good health. These, and the

457 wider problems associated with PD could therefore put men's bodies at odds with what were  
458 accomplish idealised or hegemonic forms of masculinity .

459

## 460 **Discussion**

461 Men's experience of PD can be explored through the intersections of age and gender relations and  
462 their implications for men's embodiment. In PD the habitual experience of the absent body breaks  
463 down. Among the men in this study, this dys-appearance took on a gendered character (Leder 1990;  
464 Solimeo 2008). Men's bodies struggled with a number of bodily processes previously hidden deep  
465 within the visceral body, with several leading to difficulties with, or even the loss of control over bodily  
466 functions taken for granted within the absent masculine body (Chapple & Ziebland 2002). PD also  
467 affected the body's ability to accomplish a pragmatic embodiment defined through masculine  
468 occupations and labours and threatening the gender roles and biographical identities derived from  
469 them. Furthermore, the changes occurring in men's visceral and pragmatic embodiments led to shifts  
470 in their experiential states, leading to a fluctuating, embodiment.

471 Gender and age relations also intersected within men's embodiment, together influencing how men  
472 made sense of their changing bodily experiences. Masculine bodily norms associated with youth and  
473 early middle age such as strength, stamina, and the taken-for-grantedness of intimate bodily functions  
474 remained important to men regardless of age. However older and younger men engaged with these  
475 norms from differing embodied and ageing standpoints. Cultural discourses of ageing and in particular  
476 of an age-based decline were drawn on as a means of comprehending many of the various bodily  
477 changes occurring in PD. These discourses and the expectations based on them however also served  
478 to maintain and even reassert age appropriate forms of masculinity (Emslie *et al* 2006; Spector Mersel  
479 2006). By comprehending and accepting PD as part of the ageing process, PD could be considered as  
480 Faircloth *et al* (2004) terms a 'normal crisis'; part of the natural trajectory of older age rather than an

481 illness event inherently disruptive to personal biography. In doing so, older men could avoid or resist  
482 narratives of illness while also maintaining a masculine biographical self; for example by  
483 demonstrating the virtues of bravery, humour, stoicism and struggle in the face of their growing  
484 physical limitations. In contrast, for men with PD in middle and early old age, the expected declines  
485 of older age provided a closer opportunity to comprehend PD's lived experience than their  
486 expectations of illness. However PD meant these declines were all now happening much earlier in life  
487 than they should (Singer 1974; Solimeo 2009). Men with PD in middle age struggled to draw upon a  
488 shared narrative of bodily ageing in ways which could successfully account for their difficulties. The  
489 abnormality of bodily decline relative to ages left men in middle age unable to meet embodied  
490 expectations of given their stage in the lifecourse, while simultaneously lacking the discourses of  
491 acceptable male ageing that older men could use to account for their declining bodily states (Calasanti  
492 & King 2005).

493 Importantly, the progressive nature of PD, alongside the sensitive nature of some PD symptoms meant  
494 that PD had ongoing, continual and unstable effects both on men's bodies and men's continuing  
495 embodiment. As symptoms arose, as abilities declined, and as bodies changed in the way they  
496 responded to medications, the changes occurring in men's bodies required a frequent re-negotiation  
497 and reconstruction of identity (Bury 1982; Faircloth *et al* 2004). Eventually PD could cease to be a  
498 'normal crisis', as it overtook men's ability to either reassert their masculinity or to mobilise discourses  
499 of age-based decline in order to explain their difficulties. Men could make light of tremor as '*its just*  
500 *the parkies*', but symptoms such as incontinence, off periods or hypersexuality challenged ideals about  
501 (men's) bodies and so could not so easily be explained away. As such symptoms developed, men  
502 across the lifecourse increasingly struggled to locate PD within their expectations of physiological  
503 decline for men of their ages; a, as abilities and activities were lost faster than they could compensate  
504 for them, or as they lost control over the intimate bodily functions. Age and gender therefore  
505 intersected shaping both how the physiological effects of PD came to be known, and determining the

506 options available to men when responding to these effects (Solimeo 2008). Studies of masculinity and  
507 health should therefore explore how masculinities both challenge *and* sustain men's identities, the  
508 ongoing nature of this process, and how this process changes as progressive illnesses develop and as  
509 men age (Emslie *et al* 2006; Robertson *et al* 2010).

510 It is important to note the limitations of this paper. While ethnicity, sexuality or class also intersect  
511 with age and gender relations they are not explored here, nor have they been explored in the wider  
512 literature (King & Calasanti 2013). Not least, the fact that all of the men in this sample defined  
513 themselves as heterosexual limits our ability to examine how non heterosexual men may have  
514 experienced PD, and provides an important opportunity for further research regarding PD's lived  
515 experience. Local service designs meant men with young onset PD were referred to neurology services  
516 instead of the movement disorder or geriatric clinics taking part in the clinical study, meaning men  
517 with young onset PD (onset <40yrs) could not be easily recruited. While 3 men with young onset PD  
518 were approached they either refused to participate (1) or withdrew due to ill health (2). This limits our  
519 discussion of PD's lived experience among men of younger ages. Given the paucity of age-sensitive  
520 services and in particular services providing support appropriate to men with young-onset PD, further  
521 study of how men with young-onset PD engage with masculinities and their implications for PD care is  
522 warranted.

523 This paper supports the findings of Solimeo (2008) in which those symptoms with greatest impact on  
524 masculinity were linked to men's continuing masculine gender roles. However these gender roles had  
525 wider implications for men's embodiment, including how their bodies appeared, how they functioned  
526 and how they felt. Gender and ageing are particularly salient, shaping both how PD is produced as a  
527 problem in men's lives and how they should respond. In particular, illustrating the effect on a  
528 masculine embodiment of PD's non motor symptoms, and the various effects routine therapy has on  
529 men's embodiments gives insights for the future development of therapeutic services able to meet  
530 men with PD's needs as they move through the lifecourse.

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