



## Ageing, Masculinity and Parkinson's Disease: Embodied Practices

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

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3 1 **Title: Ageing, masculinity and Parkinson's Disease: Embodied perspectives**

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8 3 **Abstract**

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12  
13 5 older men's lived experiences of PD, including how they are influenced by age and gender relations  
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17 7 how men engage with masculinities and ageing in order to make sense and meaning from PD. Data is  
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3 21 **Introduction**  
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6 22 Historically classified as a movement disorder, Parkinson's disease (PD); a chronic, progressive  
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8 23 neurological condition whose major symptoms (muscular rigidity, tremor and akinesia) affect  
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10 24 movement and mobility is increasingly being recognised as an illness affecting the totality of a  
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12 25 person's life (Jankovic 2008). Yet despite increased attention within clinical research on PD's non-  
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14 26 motor symptoms, PD's routine care remains focused on alleviating motor symptomology through  
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16 27 drugs (Playfer 2007; Parkinson's UK 2011). Exacerbating this trend, clinical research in PD has largely  
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18 28 failed to engage with PD's lived experience, demonstrated in the divergence between the  
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20 29 condition's clinical priorities and patients own concerns (Abudi *et al* 1997; Bramley & Eatough 2005;  
21  
22 30 Solimeo 2008; Stanley Hermanns & Engbretson 2010). Although having much to offer, sociological  
23  
24 31 approaches exploring chronic illnesses as situated within social practices have not yet critically  
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26 32 engaged with PD, meaning our knowledge of PD as a condition embedded within the social world  
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28 33 has been under-explored (Solimeo 2009).  
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32 34 Age and gender relations have particular salience in PD. PD has been indexed to the process of  
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34 35 ageing. With an age of onset of typically around 60 years, advancing age is the only risk factor  
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36 36 consistently associated with the disease (Hindle 2010). In addition, prevalence studies suggest that  
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38 37 PD affects 1.5 to 2 men for every woman, with men also reporting worse symptoms and poorer  
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40 38 quality of life (De Lau & Breteler 2006; Haaxma *et al* 2007). PD's symptomology has been described  
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42 39 using sex or age based epidemiological differences (Haaxma *et al* 2007) or via problems distinct to  
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44 40 the sexes, such as menstruation or erectile dysfunction (Meco *et al* 2008). Yet despite organising  
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46 41 much of PD's symptomology, the impact of age and gender as relations have thus far been neglected  
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48 42 (Solimeo 2008). PD therefore gives us an opportunity to explore how age and gender intersect in the  
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50 43 context of chronic illness (Hearn 2009; Solimeo 2009; Calasanti 2010).  
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55 44 Embodied perspectives provide an important route to elaborating the role age and gender play in  
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57 45 chronic illness (Merleau Ponty 1962; Leder 1990; Toombs 2002). Despite this, it is only relatively  
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3 46 recently that men's specific embodiment in relation to health has been subject to critical enquiry  
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5 47 (Courtenay 2000; Robertson 2006). Watson's 'male body schema' (2000), further developed by  
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7 48 Robertson (2006; 2007; Robertson *et al* 2010) has been advanced as a useful starting point. In the  
8  
9 49 male body schema, a normative embodiment or idealised experience of the male body is constituted  
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11 50 by three inter-related dimensions; a visceral embodiment or the physiological processes constituting  
12  
13 51 the male body, a pragmatic embodiment defined by men's bodily capacity to complete everyday  
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15 52 tasks and an experiential embodiment reflecting the vividness of bodily sensations. These  
16  
17 53 distinctions are not mutually exclusive, instead they interact with each other to shape the ways in  
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19 54 which men inhabit their bodies, doing so at different times and in different contexts (Robertson *et al*  
20  
21 55 2010).

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26 56 Although research on men's embodiment is now growing, the study of masculinities as men age  
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28 57 remains in its infancy (Thompson 2007; Calasanti 2010; Tarrant 2014). Originating within feminist  
29  
30 58 gerontology, a limited body of work has theorised age and gender as intersecting processes  
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32 59 (Calasanti 2005; Krekula 2007; King & Calasanti 2013; Tarrant 2014). Studies have explored  
33  
34 60 commonalities in men's ageing such as grandfatherhood (Scraton & Holland 2006), widowhood  
35  
36 61 (Bennett 2007) and the provision of spousal care (Russell 2007), yet the embodiment of gender and  
37  
38 62 ageing within chronic illness remains under-studied (McVittie & Willock 2006; Hurd Clarke & Bennett  
39  
40 63 2013). The consequences of illness are as much linked to cultural processes and discourses attached  
41  
42 64 to bodies as they are to visceral changes, meaning both physiological changes and social practices  
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44 65 together inform our understandings of men's embodiment as they age (Calasanti 2005; Solimeo  
45  
46 66 2009). A small body of work has explored the importance of gender and age relations in PD.  
47  
48 67 Solimeo (2008) has illustrated how, despite experiencing similar symptom profiles and effects on  
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50 68 quality of life, men and women experience PD from differing gendered standpoints. Women's  
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52 69 accounts of PD were situated within domestic responsibilities and a collective, family identity. In  
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54 70 contrast, men focused on the body's functionality, declines in traditional male roles and men's  
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3 71 withdrawal from social relationships. PD has also been situated within cultural patterns of ageing.  
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5 72 Describing PD as 'premature social ageing', Singer (1974) describes how PD is understood through  
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7 73 social expectations of bodily decline conventionally associated with an older age, but which in this  
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9 74 case are felt far earlier in the lifecourse. Solimeo (2009) draws out tensions when using discourses  
10  
11 75 of ageing to account for PD's lived experience, with PD both accelerating the physiological  
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13 76 experience of ageing while also obscuring the natural ageing process, creating confusion regarding  
14  
15 77 the boundaries between PD's pathology and typical bodily ageing.  
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19 78 Building on the literature in men's health and the nascent study of ageing masculinities, this paper  
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21 79 explores men's experiences of PD in terms of a masculine, ageing embodiment. Drawing on visceral,  
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23 80 pragmatic and experiential dimensions of the male body schema, this paper discusses how PD is  
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25 81 experienced in relation to a masculine embodiment, which in turn intersects with cultural discourses  
26  
27 82 and expectations relating to ageing.  
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### 31 **Methods**

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34 84 This paper reports findings from a project exploring men's experiences of living with PD  
35  
36 85 (ANONYMISED REF 2013). Thirty interviews were carried out with 15 men in 2011-2012.  
37  
38 86 Participants were identified from a sub-sample of 100 men taking part in a clinical study  
39  
40 87 investigating mood disorders in PD (ANONYMISED REF 2011). Participants attended outpatient PD,  
41  
42 88 geriatric and movement disorder clinics in North West England and North Wales. A maximum  
43  
44 89 diversity sampling approach drew on clinical research data to capture as wide a range of PD  
45  
46 90 symptomology as possible, without reliance on a convenience sample. The sample was stratified  
47  
48 91 according to age, PD severity, PD duration, and presence of motor and non-motor symptoms (table  
49  
50 92 1). Ethical approval was given by NHS South Manchester Research Ethics Committee (MREC number  
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52 93 ANONYMISED).  
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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)

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

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3 103 The study adopted a phenomenological approach using narrative methods (Mishler 1986; Riessman  
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5 104 1993). Drawing on Wengraf's (2001) biographical narrative interview methodology each man took  
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7 105 part in an initial narrative interview followed by a semi-structured interview which further  
8  
9 106 investigated narrative themes. Interviews lasted 1-4 hours and were conducted by the first author.  
10  
11 107 Follow up interviews took place 1-3 months after initial analysis of narrative interviews. Interviews  
12  
13 108 were audio recorded and transcribed verbatim. All participants were given the opportunity to  
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15 109 comment on their transcripts, with two men doing so.

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19 110 Analysis was carried out by the first author with regular discussion with the second author. Taking  
20  
21 111 as a starting point the idea that PD disrupts a taken-for-granted or 'absent' embodiment (Leder  
22  
23 112 1990), the study explored men's stories about living with PD and how gender and ageing were  
24  
25 113 'emplotted' within these stories (Mattingly 1998). Narratives were organised into themes using  
26  
27 114 Watson's (2000) male body schema. Transcripts were separated into individual stories relating to a  
28  
29 115 specific activity or experience. These stories were then organised into themes such as, occupations,  
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31 116 bodily sensations, emotions and moods. Themes were then organised in relation to visceral,  
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33 117 pragmatic and experiential dimensions of embodiment. Findings are discussed in three sections. First  
34  
35 118 we explore PD's implications for a visceral embodiment which in turn are influenced by expectations  
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37 119 of men's ageing. We then discuss a pragmatic embodiment, in which men drew on masculine  
38  
39 120 occupations to comprehend PD's losses and reassert a masculine identity. Finally we discuss an  
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41 121 experiential embodiment, where the emotions and sensations attached to PD's symptoms led to a  
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43 122 fluctuating bodily state which in turn threatened masculinity.

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51 124 **Results**

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54 125 ***PD and a visceral embodiment***  
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3 126 A visceral embodiment refers to the underlying biological and physiological processes supporting the  
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5 127 'real' physical body, and their implications for men's identities (Robertson 2006). Men's accounts of  
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7 128 PD frequently began with its effects on the body's physical ability to move;

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10  
11 129 *Bob: I don't know if I can blame Parkinson's for my walking. If it is Parkinson's that's*  
12  
13 130 *causing my walking, then it has affected me, and it is affecting me more. And balance as*  
14  
15 131 *well. It's as if I am carrying one tonne shoes. Yeah. It's just, I'm walking, you know, zig*  
16  
17 132 *zagging, I feel that, and I don't think that that is just old age.*

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19  
20 133 Other difficulties included shaking, stiffness in the muscles, losing stamina or fatiguing easily, all  
21  
22 134 leading men to describe the body as feeling shaky, heavy or slow. When describing these difficulties,  
23  
24 135 men frequently referenced the physiological declines expected in older age. Asked how PD affected  
25  
26 136 his walking Harold claimed 'well I am eighty you know'. Men's stories also conflated PD with ageing,  
27  
28 137 at times making it hard to separate which problems were PD-related and which were the result of  
29  
30 138 'just old age';

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34 139 *Peter: It's annoying, I'm walking along, and I see people, this little old lady, and I say*  
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36 140 *to myself, they're walking slowly, but they're overtaking me, and the next thing I think*  
37  
38 141 *I'm slower than them (laughs). They're walking slowly, so I must be walking even more*  
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40 142 *slowly. And I used to be able to stride away. (...) It's just this old chap shuffling along,*  
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42 143 *that's me. I expected to be slow, but not this slow.*

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45 144 Peter compared the slowing he experienced to people of a similar age to himself, finding himself  
46  
47 145 slower than he expected to be given his age. Men in middle age also drew on expectations of bodily  
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49 146 ageing to describe difficulties with movement. Aged 53, Simon described the problems associated  
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51 147 with crossing a road;

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55 148 *Simon: When I'm in town I'll stop at the village, in the road, and I'll look, and I'll look,*  
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57 149 *and I'll look again. Because you know that when you walk across the road sometimes*  
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3 150 *you don't walk as quickly as you want to, and you can't actually make yourself hurry, so*  
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5 151 *you make sure it's safe to cross. Whereas I suppose if I was a typical elderly person, I*  
6  
7 152 *would just cross slowly and people would have to pull to a halt while I carried on crossing*  
8  
9 153 *obliviously. So that's me saying, it's ageing me in that respect.*  
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11

12  
13 154 Simon's orientation to crossing a road had now changed, his having to be more cautious, taking  
14  
15 155 more time to cross. Yet while Simon judged his problems as an expected part of later life, he did not  
16  
17 156 expect to face such difficulties given his relatively young age. Both older and younger men  
18  
19 157 therefore expressed that they felt slower than they expected they should be, experiencing their  
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21 158 body as something 'other' than their selves, given their respective ages.  
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24  
25 159 PD also affected a number of the body's most intimate bodily functions. Rather than PD's better  
26  
27 160 known motor symptoms, it was difficulties with drooling, incontinence and sexual dysfunction that  
28  
29 161 posed the most explicit challenge to a masculine self-image. Aged 55, Roger described incontinence  
30  
31 162 as a clear threat to his masculinity;  
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34 163 *Roger: Getting to the toilet in time. You know, it's a simple thing but it erodes your*  
35  
36 164 *masculinity a little bit doesn't it. You know. So why I wear white trousers I dunno. Simple*  
37  
38 165 *things like that, if you happen to be weak, it takes a hell of a lot of bladder control. I can*  
39  
40 166 *just about make it, but sometimes you fail. It doesn't do anything for your masculinity*  
41  
42 167 *does it.*  
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46 168 A common problem in PD, incontinence required intimate bodily management. Men frequently  
47  
48 169 reported having to avoid public spaces lacking toilets or be watchful for bodily sensations indicating  
49  
50 170 the need to urinate/defecate. Roger conveyed how utterly exposing incontinence could be within  
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52 171 public domains.  
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3 172 *Roger: God forbid if I have white trousers on and I go for a piss, and spill a bit stuff*  
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5 173 *like that, so, and if I'm fidgety, you think everybody sees it, you know. I think everybody's*  
6  
7 174 *looking at me, cos I know they are.*  
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10  
11 175 Henry also described an incidence of incontinence when buying a car far from home.

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13 176 *Henry: I went to get out of the car and I was soaking wet. Absolutely soaking wet, my*  
14  
15 177 *bladder had let loose (...). So now I'm in a position I'm soaking wet, I'm a long way from*  
16  
17 178 *home, I'm fed up, so do I go home or what. So I rang them and I said "look I'll tell you*  
18  
19 179 *straight now, I've got Parkinson's disease, I've just had a mishap in as much as my*  
20  
21 180 *bladder's just let go, I'm soaking wet, if you don't want to see me I quite understand, but*  
22  
23 181 *I can't come back all this way again, so it's now or never sort of thing". (...) I can honestly*  
24  
25 182 *say coming away from there they were very friendly people, (...) there were three men*  
26  
27 183 *there that I was dealing with, two of them had got experience of Parkinson's in the*  
28  
29 184 *family, and they wanted to know more.*  
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34 185 *The experience of incontinence threw into relief a man's image of himself and his expectations of*  
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36 186 *appropriate conduct. In Henry's account, incontinence called for an honest approach, recognising*  
37  
38 187 *that there was little he could do to hide it. In such circumstances, Henry preferred to attribute the*  
39  
40 188 *problem to his PD rather than his age. Indeed telling people that incontinence was a symptom of his*  
41  
42 189 *PD rather than a by-product of advanced age elicited a more sympathetic response. By discussing*  
43  
44 190 *incontinence in this way, men could at least try to legitimise its experience as part of a disease*  
45  
46 191 *process, rather than a personal failing (Roger) or part of the ageing process (Henry). However a*  
47  
48 192 *number of men in mid-life struggled to manage the stigma associated with incontinence, even after*  
49  
50 193 *blaming it on PD. Roger continued to feel embarrassed about his incontinence, even when telling*  
51  
52 194 *others it was part of his illness. In his fifties, neither Roger nor his family or friends could associate*  
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54 195 *Roger's incontinence with the bodily declines expected in older age.*  
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3 196 As with incontinence, the bodily changes associated with sexual function were influenced both by  
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5 197 PD's symptomology and by men's expectations of appropriate sexual activity as they aged. Almost  
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7 198 all of the men with PD in this study described at least some difficulties, either with erectile  
8  
9 199 dysfunction or changes in sexual desire. Most men positioned these problems as a natural part of  
10  
11 200 the ageing process. Peter couldn't maintain an erection, but claimed this posed greater problems  
12  
13 201 for 'pissing' than sex;

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16  
17 202 *Peter: Severe erectile dysfunction, which is, I can't even pee properly now, I have to*  
18  
19 203 *drag myself out, which is very annoying, yeah.*

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21  
22 204 *Int: Does erectile dysfunction impact other aspects of your life?*

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25 205 *Peter: No, I mean I don't have sexual intercourse, that sort of thing. Well apart from*  
26  
27 206 *going out and buying some Viagra do you mean! (laughs).*

28  
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30 207 For older men, sex was spoken of, at least initially, as something that was now 'long past' (Bob).  
31  
32 208 Alternatively men claimed that they were 'a bit old for that now' (Harold), or 'a bit long in the tooth  
33  
34 209 for that sort of thing' (Henry). Others laughed at the fact that their doctors regularly asked them  
35  
36 210 about sex. This didn't mean intimate relationships weren't important, but rather that they were  
37  
38 211 focused on loving companionship rather than continuing physical intimacy. However, complicating  
39  
40 212 this shared interpretation, many of the same older men described a continued, and in some cases  
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42 213 increased desire for sex. Albert described still having a libido;

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46 214 *Albert: well I do have a libido still. Most people do, even though they might not be*  
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48 215 *able to perform, either with advancing age or advancing Parkinson's disease, the ability*  
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50 216 *to perform decreases, but libido does not necessarily decrease. It doesn't mean that you*  
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52 217 *can actually do anything, raise to an err, you know, could have unfortunate*  
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54 218 *consequences like fathering an unwanted child. You can't do anything dramatic, but you*  
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3 219 *may feel a little bit turned on, and be a bit naughty in the way you talk to people or, err,*  
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5 220 *flirt with them for example.*  
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8 221 *Albert argued that while his ability to have sex may be in decline he still experienced sexual desire as*  
9  
10 222 *a natural part of his masculinity. Later in the same interview Albert also revealed he had recently*  
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12 223 *started watching pornography;*  
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15  
16 224 *Int: You mentioned that you'd been viewing pornography.*  
17

18 225 *Albert: Yeah. I mean is there any man who doesn't occasionally. I don't anymore*  
19  
20 226 *because it's rather boring.*  
21

22 227 *Int: Was that relatively recently?*  
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24 228 *Albert: It's a substitute for the actual thing isn't it.*  
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26  
27 229 *Int: Is it recently you were doing that?*  
28

29 230 *Albert: Yes. I used to be scornful of it; it's an old man's hobby isn't it. So called adult*  
30  
31 231 *films, I watched them three or four times, and my wife found out from the bank*  
32  
33 232 *statements and told me in no uncertain terms to stop it, so I did.*  
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35 233 *Viewing pornography is explained by Albert as the expression of a healthy masculinity and a means*  
36  
37 234 *of sustaining his libido in the face of a declining sexual relationship. But, at the same time, Albert*  
38  
39 235 *described pornography as an 'old man's hobby' which he had been forced to stop by his wife, what*  
40  
41 236 *some authors refer to as an expression of the sexualised stereotype of the 'dirty old man' (Calasanti*  
42  
43 237 *& King 2005; Sandberg 2016). In a final complication, while Albert thought his levels of desire were*  
44  
45 238 *unproblematic, he also mentioned his wife's concern over what she saw as increasingly out of*  
46  
47 239 *character and possibly due to his PD. Changes in sexual function in PD therefore occurred in the*  
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49 240 *context of both healthy and unhealthy forms of male ageing, and of pathological changes occurring*  
50  
51 241 *in PD.*  
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3 242 In contrast men in middle age clearly described sexual difficulties as a threat to their masculine  
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5 243 status. Roger worried about his declining libido;

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8 244 *Roger: I suppose from the sex point of view I suppose, I find that you're losing, what's*  
9  
10 245 *the word, libido is it. Losing a little bit of that. It bothers me from time to time when I*  
11  
12 246 *want sex. I don't dwell over it, I think she's satisfied, well I am. But I don't know. Yeah. I*  
13  
14 247 *think we're happy.*

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18 248 Roger worried about whether he could 'satisfy' himself and his wife, showing concern over both his  
19  
20 249 ability to have sex and changes in his libido, which he still expected to enjoy given his age. Recently  
21  
22 250 remarried, sex was an important part of Roger's masculine self-image, but was now under threat  
23  
24 251 from his condition. Men's stories about sexual function also went beyond the physical act of sex to  
25  
26 252 illustrate how PD also threatened men's sense of themselves as sexually attractive beings. In middle  
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28 253 age but recently widowed, Simon hoped to meet another partner:

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32 254 *Simon: I lost my wife in July, but I would like to at some point meet another partner. I'd*  
33  
34 255 *like to think that if I've got another twenty years on this planet I don't want to do it*  
35  
36 256 *alone. (...) but owning up to Parkinson's is going to be the kiss of death to any*  
37  
38 257 *relationship. I question whether I'm actually, what's the word. I suppose tarnished goods*  
39  
40 258 *is probably the best expression. Damaged property.*

41  
42  
43  
44 259 Simon feared his PD would prevent another partner committing to a relationship with him, making  
45  
46 260 him 'damaged property'. PD therefore limited Simon's belief in his ability to attract a future partner  
47  
48 261 and to pursue the range of intimate relationships felt appropriate to his age. In affecting intimate  
49  
50 262 processes and previously taken for granted bodily functions, PD therefore threatened a visceral  
51  
52 263 masculine embodiment based on men's ability to control the body in public space, alongside men's  
53  
54 264 ability to remain as sexually active beings in the context of their ages.

265

266

**267 PD and a pragmatic masculine embodiment**

268 A pragmatic masculine embodiment is concerned with the use of the body as a resource for the  
269 completion of physical, masculine activities and the gender roles through which they are sustained  
270 (Connell 1995; Watson 2000; Robertson 2006; Wiersma & Chesser 2011). Alongside its physiological  
271 effects, PD's symptoms came to be known through their effects on the body's ability to complete a  
272 range of stereotypically masculine forms of labour and the identities expressed through them. Tony  
273 described PD's effect on his ability to accomplish 'heavy work';

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

279 Men's stories frequently focused on PD's consequences for men's work, defined through  
280 employment, tasks including DIY or gardening, skilled technical work such as car maintenance,  
281 electrical rewiring or plumbing, or sports and hobbies like golf, bowls or rambling. Lacking strength  
282 and stamina, tasks such as lifting, carrying or digging became more difficult. Tremor restricted  
283 dextrous, skilful work, while fatigue left men struggling to keep up with others. But importantly men  
284 also tried to show what they could still do;

285 *Dafydd: it was wiring a plug, that's the simplest thing in the world, wiring a plug. But*  
286 *because of the way I couldn't grip properly, I had to find all sorts of ways of manipulating*  
287 *the screwdriver, very frustrating. Over the years I think I improved, I can still put a wire in*

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3 288 *a plug, purely and simply because of what I've learnt. What I've learnt is that the body,*  
4  
5 289 *and the brain, can be trained to organize a job, to do it in a different way.*  
6  
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8  
9 290 Dafydd could find new ways to use his body in order to complete his tasks. Tony tried to stoically  
10  
11 291 carry on with 'heavy things' despite their difficulty. By promoting their successes, men could show  
12  
13 292 how they overcame the limitations of their PD, keeping familiar elements of a biographical identity  
14  
15 293 intact while also maintaining a masculinity based on physical activities (Emslie *et al* 2006).  
16

17  
18 294 PD's progressive character meant that men inevitably faced increasing difficulties in continuing with  
19  
20 295 their occupations. In such cases, men's stories tried to describe losses in ways which preserved a  
21  
22 296 masculine identity. As more strenuous leisure pursuits were lost, John, David, Phillip and Harold took  
23  
24 297 up less demanding activities such as bowls, croquet or snooker;  
25  
26

27  
28 298 *John: But I'm now giving golf up. My next move is to crown green bowls, cos (wife)*  
29  
30 299 *wants to play that, so I shall play it.*  
31

32  
33 300 *Int: So as you have to give up some things...*  
34

35  
36 301 *John: I'll move on to the next.*  
37

38  
39 302 However as PD's symptoms continued to worsen, it inevitably became harder for men to sustain  
40  
41 303 their efforts. Attempts to do things in new ways often failed, while past hobbies became too tiring  
42  
43 304 or difficult to continue with. For some, the loss of physical activity could eventually threaten who  
44  
45 305 they considered themselves to be. A retired carpenter, Ian grew upset as he spoke about losing  
46  
47 306 abilities associated with his trade:  
48

49  
50  
51 307 *Ian: (becomes tearful). But it's the physical demand of doing things that I can't*  
52  
53 308 *cope with. Things that you wouldn't give a second thought to when you were fit, but*  
54  
55 309 *now I have to think, how can I get round this, and how can I get round the other, and*  
56  
57 310 *how can I do this, and how can I do that, I've got to be thinking all the time, to work out*  
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3 311 *solutions, and I tried putting a bell on the front door, that's as far as I got, it won't work.*

4  
5 312 *I've had it on and off and on and off and on and off and I can't get it to work at all.*

6  
7  
8 313 Fitting a doorbell was something Ian felt he should be able to accomplish no matter his age. While  
9  
10 314 older men could again blame some loss of activities on the natural declines of ageing, younger men  
11  
12 315 expected to be much more active. Alternatively, men could find themselves struggling with  
13  
14 316 occupations which they felt they should be able to accomplish regardless of age, either because of  
15  
16 317 their simplicity or because of their attachment to men's biography. By challenging men's ability to  
17  
18 318 carry out tasks central to both individual identities and idealised forms of masculinity, PD threatened  
19  
20 319 a pragmatic embodiment defined through men's labours.  
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28 321 ***PD and an experiential embodiment***

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31 322 Experiential embodiment concerns the sensations felt within the body, the emotions felt through  
32  
33 323 the body, and feelings attributed to the body as it interacts with the world (Robertson 2006).  
34  
35 324 Changes in visceral and pragmatic embodiments were also accompanied by changes in an  
36  
37 325 experiential embodiment. Alongside its physiological symptoms, bodies in PD no longer felt 'sharp';  
38  
39 326 able to respond quickly to the world around them. Arms and legs were no longer able to move  
40  
41 327 quickly and effortlessly, instead feeling laboured and heavy, what Bob called '*wearing one tonne*  
42  
43 328 *shoes*'. Men with PD also described adopting a new attunement to the body. Peter described having  
44  
45 329 to verbally tell his body how and when to move:  
46  
47

48  
49 330 *Peter: When we have drinks she can't carry them, so I carry them in, and what I find*  
50  
51 331 *interesting, whenever I'm holding something. Now I used to just let go, but sometimes he*  
52  
53 332 *doesn't let go, I have to say 'let go hand', so to speak. (...) It's definitely different.*  
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3 333 The increasing experience of the body as an object separate to the self and needing to be  
4  
5 334 manipulated and worked through was present in many of the men's stories (Anonymous ref 2016).  
6  
7 335 The body itself increasingly had to be thought about, instructed and managed. Peter found himself  
8  
9 336 having to pay attention to his hand as it picked up a cup, rather than to the cup itself. Rather than  
10  
11 337 simply and unconsciously interacting with the various objects in the world, these familiar aspects of  
12  
13 338 navigating and negotiating the world became strange, the source of a new and embodied interaction  
14  
15 339 with the self. In fact, he anthropomorphises this part of the body and gives it agency. Thoughts and  
16  
17 340 memories were also affected in similar ways, some of the men feeling increasingly out of place as  
18  
19 341 memories were forgotten or took longer to be recalled, or as conversations needed greater  
20  
21 342 concentration and effort. Hugh struggled to keep up in conversations with family or friends:  
22  
23  
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25  
26 343 *Hugh: You are in conversation with somebody, and all of a sudden you've forgotten*  
27  
28 344 *the name completely. It could be somebody well known, who you've worked with, and*  
29  
30 345 *you just can't. I go through the alphabet sometimes trying to memorise names. (...) It's*  
31  
32 346 *unpredictable, if you start a conversation and half way through, 'oh what's he talking*  
33  
34 347 *about', it's gone from your mind. It happens quite often, especially when you are in*  
35  
36 348 *company. It's embarrassing that.*  
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40 349 Men's experiential embodiment were also closely related to the experience of taking PD's various  
41  
42 350 medications. Rather than returning bodies to a taken-for-granted good health, PD's various  
43  
44 351 medications could be 'felt' to work. Alongside improving physical functioning, the sudden influx of  
45  
46 352 artificial dopamine in the brain led to often vivid bodily sensations, what Hugh described as  
47  
48 353 'returning back to the planet' and David called 'kicking in':  
49  
50

51 354 *David: When they kick in, you feel as if a weight comes off your body, and you feel,*  
52  
53 355 *ahh, I can move. But it isn't a weight, it's like a restriction, and it frees itself, gradually,*  
54  
55 356 *and all of a sudden you find you can move your legs much more easily, and you can walk*  
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3 357 *more naturally. It comes on very quickly, but then it dies down slowly after that. (...) If I*  
4  
5 358 *keep taking my tablet at the right time, it keeps me going.*  
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8  
9 359 During these states, what have been called 'on' periods within PD's routine therapy, PD's physical  
10  
11 360 symptoms subsided. Tremor could disappear while muscular stiffness also reduced, allowing the  
12  
13 361 body to move more freely (Matson 2002). Several men described feeling a 'boost', in which bodies  
14  
15 362 felt much quicker than before. Alongside these changes the body seemed to relax, as though losing  
16  
17 363 a heavy weight or feeling 'good' or 'free'. Yet as PD progressed, larger doses were required in order  
18  
19 364 to gain the same therapeutic benefit. As dosages grew, bodies could move 'too much'; exemplified  
20  
21 365 by involuntary tics or jerks known as dyskinesia. *During on states bodies could also feel*  
22  
23 366 *'hyperactive';*  
24  
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26  
27 367 *Hugh: You're hyperactive then. You just want to do things, and get things and do*  
28  
29 368 *things that don't really need doing. You see something that's broken down, you want to*  
30  
31 369 *repair it that minute, you can't leave it till the next day.*  
32  
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34  
35 370 During on states men could feel 'driven', 'buzzing' or 'wired', sensations accompanied by a range of  
36  
37 371 impulsive desires described by Henry as 'doing too much';  
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39  
40 372 *Henry: (consultant) and my wife got their heads together and my wife's theory was*  
41  
42 373 *that my Parkinson's was being aggravated by the very fact that I was doing too much.*  
43  
44 374 *One of the things I was doing was buying and selling cars, which I used to earn a living*  
45  
46 375 *at. At a time when I should have been retired and relaxing, I was going out and buying*  
47  
48 376 *two or three cars in a day and putting them on sale and moving them around garages.*  
49  
50 377 *She mentioned it to (consultant), and he said, 'well why are you doing it if you don't*  
51  
52 378 *mean to do it'. 'I don't know really, I've got to keep going like', and he thinks that its*  
53  
54 379 *related to the compulsive behaviour that some people get, the gambling, some get it*  
55  
56 380 *with sex, some get it with shopping or what have you.*  
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3 381 Other men experiences similar sensations. Tom found himself *'flittering'*, unable to focus on any  
4  
5 382 one thing and struggling to complete his daily tasks. Henry and Roger wanted to spend money  
6  
7 383 unnecessarily while Hugh had gambled uncontrollably, losing large amounts of money. These  
8  
9 384 experiences were often distressing, leading men to seek help from their medical practitioners. Yet in  
10  
11 385 practice beyond reducing the frequency or strength of medications there was little medical staff  
12  
13 386 could do to assist them. In such cases men either had to put up with them, using what Hugh called  
14  
15 387 *'mind over matter'* or reduce their medication dosages, reducing such experiences but exacerbating  
16  
17 388 motor symptoms.

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20  
21 389 As medications 'kicked in' they also 'wore off'. David described what the 'wearing off' phenomena  
22  
23 390 in PD felt like;

24  
25  
26  
27 391 *David: Oh, hopeless. Well imagine holding a potato, and peeling it, and you haven't*  
28  
29 392 *got any strength to press the peeler against the potato. Everything slows down. And you*  
30  
31 393 *sometimes feel your feet are like lead weights, they're there, but they seem to stick to*  
32  
33 394 *the floor.*

34  
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36  
37 395 Once medications wore off, PD's symptoms returned, while bodies seemed to suddenly slow down,  
38  
39 396 once again feeling heavy or empty of energy. Wearing off could sometimes be solved by taking  
40  
41 397 medications earlier than prescribed or overdosing. However overdosing could be risky with  
42  
43 398 repercussions for their bodies for the rest of the day. As PD advanced wearing off developed into  
44  
45 399 'off periods', in which medications suddenly and unpredictably lost their efficacy (Matson 2002).  
46  
47 400 During off periods Hugh felt *'like a zombie'*;

48  
49  
50  
51 401 *Hugh: It just comes on like a light switch. One minute you'll be fine, the next minute*  
52  
53 402 *you're like a zombie. And my partner notices it straight away. She's only got to look at*  
54  
55 403 *me, she can tell. They feel terrible to be honest. (...) When you are in an off period you*  
56  
57 404 *feel so lousy it's unbelievable. Your co-ordination, you're like, you are stiff more or less,*  
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3 405 *you can't get going properly. So you just wait for (medication) to kick in and then get*  
4  
5 406 *back going again.*  
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8  
9 407 In off periods almost all movement ceased, while thinking slowed to a crawl. **Even rising from a chair**  
10  
11 408 **could be too difficult.** Once started all Hugh could do was wait out an off period, perhaps taking a  
12  
13 409 'booster' medication to try and speed its passing. For those experiencing them life increasingly had  
14  
15 410 to be planned around off states, for example curtailing any activities if they felt the tell-tale  
16  
17 411 sensations indicating the start of an off period.

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19  
20 412 Finally, PD and its symptoms could leave men struggling to **accomplish the social interactions**  
21  
22 413 **commonly taken for granted within an embodied masculine identity.** Roger ran a building company,  
23  
24 414 spending lots of time on the site with other men. Valorising a masculinity based upon a strong  
25  
26 415 physical presence and jocular, at times aggressive 'banter', Roger now felt he had to 'put up a front'  
27  
28 416 at odds with **the emotions attached to** his body;

29  
30  
31  
32 417 *Roger: In the old days these sort of problems (on the building site), fucking hell I can*  
33  
34 418 *deal with that Wednesday afternoon, no problem. I'm so conscious of that, that I'm half*  
35  
36 419 *the man I was. That's not nice (...) it's a front I have to put up, erm, it's a real front*  
37  
38 420 *because, you know, if people think you are weak they'll take advantage of you. That's*  
39  
40 421 *what I've found (...) you know it would be nice to be able to go any time you like, rather*  
41  
42 422 *than having to psych yourself up or something, yeah.*  
43  
44  
45

46 423 **For Roger, the performative nature of masculinity was brought into relief as** he struggled to 'pass  
47  
48 424 himself off' **according to what he felt were acceptable forms of masculinity.** The significance of an  
49  
50 425 experiential embodiment in PD lay in its increasingly fluctuating bodily experience, **both in its**  
51  
52 426 **abilities and in the emotions and sensations attached to it.** PD's symptoms led to numerous changes  
53  
54 427 in sensations felt through the body while PD's drug therapy also brought about further changes.  
55  
56 428 **These changes led to a new experiential embodiment, characterised by constant fluctuations**  
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3 429 between the body's sensory and emotional states. Whether pleasant or detrimental the  
4  
5 430 experiences associated with fluctuations between 'on' and 'off states' each distanced men from the  
6  
7 431 habitual experience of embodied good health, with the outcome of putting the experiential body at  
8  
9 432 odds with idealised, taken-for-granted forms of masculinity .

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13 433 **Discussion**

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16 434 This paper explores PD's implications for men's embodiment as experienced through the  
17  
18 435 intersections between age and gender relations. In PD the habitual experience of the absent body  
19  
20 436 breaks down. In turn this dys-appearance takes on a gendered character (Leder 1990; Solimeo  
21  
22 437 2008). Men's bodies struggled with a number of processes hidden deep within the visceral body,  
23  
24 438 with several leading to the loss of control over taken for granted bodily functions (Chapple &  
25  
26 439 Ziebland 2002). In doing so, PD also affected the body's ability to accomplish a pragmatic  
27  
28 440 embodiment defined through masculine occupations and labours and an experiential embodiment  
29  
30 441 based upon the stability of the body's sensory and emotional states.

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34 442 Gender also intersects with age relations, with both together influencing how men made sense of  
35  
36 443 their changing bodily experiences. Masculine bodily norms associated with youth and early middle  
37  
38 444 age, such as strength, stamina, and control over intimate bodily functions remained important to all  
39  
40 445 men regardless of age. However older and younger men engaged with these norms from differing  
41  
42 446 ageing standpoints. Cultural discourses of ageing and in particular of an age-based decline were  
43  
44 447 drawn on in order to comprehend the various bodily changes occurring in PD. In many cases, these  
45  
46 448 discourses could maintain and even reassert age appropriate forms of masculinity (Emslie *et al* 2006;  
47  
48 449 Spector Mersel 2006). By comprehending and accepting PD as part of the ageing process, PD could  
49  
50 450 be considered as Faircloth *et al* (2004) terms a 'normal crisis'; part of the natural trajectory of older  
51  
52 451 age rather than an illness event inherently disruptive to personal biography. In doing so, older men  
53  
54 452 could avoid or resist narratives of illness while also maintaining a masculine self-image; for example  
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3 453 demonstrating the virtues of bravery, humour, stoicism and struggle in the face of their growing  
4  
5 454 physical limitations. However PD posed continued challenges to these stories. For older men, age  
6  
7 455 could account for their failures. However as their illness progressed it became increasingly difficult  
8  
9 456 to blame all their difficulties on ageing. Some bodily failures, such as incontinence were too  
10  
11 457 sensitive for men to simply blame on age, indeed it was preferable to blame such problems on being  
12  
13 458 ill than being old. And finally PD could 'overtake' men's expectations of normal or typical bodily  
14  
15 459 ageing, bringing their difficulties into relief and forcing men to engage with the fact that they were  
16  
17 460 not just old, but that they were 'ill, suffering from a chronic progressive condition for which there  
18  
19 461 was no cure.

20  
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22  
23 462 Younger men also found the expected declines of older age provided a closer opportunity to  
24  
25 463 comprehend PD's lived experience than their expectations of illness (Singer 1974; Solimeo 2009).  
26  
27 464 However for younger men this sense of bodily decline was happening much earlier in life than it  
28  
29 465 should. Men with PD in middle age struggled to draw upon a shared narrative of bodily ageing in  
30  
31 466 ways which could successfully account for their difficulties. The abnormality of bodily decline relative  
32  
33 467 to their chronological ages left men in middle age unable to meet embodied expectations of life  
34  
35 468 given their stage in the lifecourse, while simultaneously leaving them lacking the discourses of  
36  
37 469 acceptable male ageing that older men could use to account for their declining bodily states  
38  
39 470 (Calasanti & King 2005).

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44 471 Importantly, the progressive nature of PD also meant that PD had ongoing, continual and unstable  
45  
46 472 consequences for men's embodiment. Unlike Bury's (1982) typical model of biographical disruption,  
47  
48 473 in which disruption occurs at onset and a new narrative reconstruction of identity takes place, the  
49  
50 474 changes occurring in men's bodies in PD demanded the continued re-negotiation and reconstruction  
51  
52 475 of identity (Bury 1982; Faircloth *et al* 2004). Men could make light of tremor as '*just the parkies*', but  
53  
54 476 as symptoms worsened, and as problems such as incontinence or off periods emerged, the problems  
55  
56 477 men's bodies faced could not so easily be explained away. Eventually PD overtook men's ability to  
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3 478 either reassert their masculinity or to mobilise discourses of age-based decline in order to explain  
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5 479 their difficulties, as abilities were lost faster than men could compensate for them, or as they lost  
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7 480 control over the intimate bodily functions. Age and gender therefore intersected in both how the  
8  
9 481 physiological effects of PD came to be known, and in the options available to men when responding  
10  
11 482 to these effects (Solimeo 2008).  
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15 483 It is important to note the limitations of this paper. While ethnicity, sexuality or class also intersect  
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17 484 with age and gender relations they are not explored here, nor have they been explored in the wider  
18  
19 485 literature (King & Calasanti 2013). Not least, the fact that all of the men in this sample defined  
20  
21 486 themselves as heterosexual limits our ability to examine how non heterosexual men may have  
22  
23 487 experienced PD, and provides an important opportunity for further research regarding PD's lived  
24  
25 488 experience. Local service designs meant men with young onset PD were referred to neurology  
26  
27 489 services instead of the movement disorder or geriatric clinics taking part in the clinical study,  
28  
29 490 meaning men with young onset PD (onset <40yrs) could not be easily recruited. While 3 men with  
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31 491 young onset PD were approached they either refused to participate (1) or withdrew due to ill health  
32  
33 492 (2). In addition, limits to the sample size and narrative data from younger men restricted our ability  
34  
35 493 to ascertain the extent to which we can understand the intersections between ageing and illness for  
36  
37 494 those in middle age. This limits our discussion of PD's lived experience among men of younger ages.  
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42 495 This paper supports the findings of Solimeo (2008) in which those symptoms with greatest impact on  
43  
44 496 men were not simply those symptoms which were most frequent. Instead those symptoms of  
45  
46 497 greatest prominence threatened men's embodiment through their ability to accomplish masculine  
47  
48 498 gender roles. However these gender roles had wider implications for men's embodiment, influencing  
49  
50 499 how men's bodies appeared to them, how they functioned and how they felt. In turn men's  
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52 500 expectations of ageing shaped how PD is produced as a problem in men's lives and how men should  
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54 501 respond to these problems. Given the paucity of gender and age-sensitive services and in particular  
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56 502 services providing support appropriate to men with young-onset PD, further study of how men with  
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3 503 young-onset PD engage with masculinities and their implications for PD care is warranted. In  
4  
5 504 particular, understanding the effect of PD's symptoms beyond its motor effects, and of PD's routine  
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7 505 therapy has on men's embodiments can give important insights for the future development of  
8  
9 506 therapeutic services more sensitive to men's differing needs.  
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For Peer Review



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