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Abstract

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 PD’s effects on men’s bodies, alongside how men engage with masculinities and ageing in order to make meaning from these experiences. 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 pragmatic embodiment expressed through men’s everyday occupations; a visceral embodiment located in difficulties with the body’s basic movements and intimate functions and an experiential embodiment concerned with emotions and sensations within and about 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.

Keywords

Parkinson’s Disease. Embodiment. Masculinity. Ageing

Word Count.
Introduction

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

Age and gender relations have particular salience in PD. PD has been indexed to the process of ageing. With an age of onset of typically around 60 years, advancing age is the only risk factor consistently associated with the disease (Hindle 2010). In addition, prevalence studies suggest that PD affects 1.5 to 2 men for every woman; men also report worse symptoms and poorer quality of life (De Lau & Breteler 2006; Haaxma et al 2007). PD’s symptomology has been described using sex or age based epidemiological differences (Haaxma et al 2007) or via biological problems distinct to the sexes, such as menstruation or erectile dysfunction (Meco et al 2008). Yet despite organising much of PD’s symptomology, the impact of age and gender relations in PD have thus far been neglected (Solimeo 2008; Davidson & Meadows 2010). PD therefore gives us an opportunity to explore how age and gender intersect in the context of chronic illness (Hearn 2009; Solimeo 2009; Calasanti 2010).
Embodied perspectives, concerned with the lived body and its experience in disease-states, provide an important route to elaborating the role age and gender relations play in informing chronic illness experiences (Merleau Ponty 1962; Leder 1990; Toombs 2002). Yet it is only relatively recently that men’s embodiment in relation to health has been subject to critical enquiry (Courtenay 2000; Robertson 2006). Watson’s ‘male body schema’ (2000), further developed by Robertson (2006; 2007; Robertson et al 2010) has been advanced as a useful starting point. In the male body schema, a normative embodiment or the idealised experience of the male body is constituted by three inter-related embodied dimensions; a visceral embodiment or the physiological processes constituting the male body, a pragmatic embodiment defined by men’s bodily capacity to complete everyday tasks and an experiential embodiment reflecting the vividness of bodily sensations. These distinctions are not mutually exclusive, instead they interact with each other to shape the ways in which men inhabit their bodies, doing so at different times and in different contexts (Robertson et al 2010).

Although men’s’ embodiment is now growing as an area of research, the study of masculinities as men age remains in its infancy (Thompson 2007; Calasanti 2010; Tarrant 2014). Originating within feminist gerontology, a limited body of work has proceeded by theorising gender and age relations as intersecting processes (Calasanti 2005; Krekula 2007; King & Calasanti 2013; Tarrant 2014). Studies have explored commonalities of experience in men’s ageing such as grandfatherhood (Scraton & Holland 2006), widowhood (Bennett 2007) and the provision of spousal care (Russell 2007). Yet the embodiment of gender and ageing within chronic illness experiences remains under-studied (McVittie & Willock 2006; Hurd Clarke & Bennett 2013). The consequences of illness are as much linked to the wider cultural processes and discourses attached to bodies as they are to visceral changes, meaning both physiological changes and social practices together inform our understandings of men’s embodiment as they age (Calasanti 2005; Solimeo 2009). A small body of work has explored the importance of gender and age relations in PD. Solimeo (2008) has illustrated how, despite experiencing similar symptom profiles and effects on quality of life, men and women’s lived
experiences of PD occupy differing gendered standpoints. Specifically women’s accounts of PD were situated within their domestic responsibilities and a collective, family identity. In contrast, men focused on the body’s functionality and declines in traditional male roles leading to men’s withdrawal from social relationships. PD can also be situated within cultural patterns of ageing. Describing PD as ‘premature social ageing’, Singer (1974) describes how PD is understood through social expectations of bodily decline conventionally associated with an older age, but in this case, felt far earlier in the lifecourse than ordinarily expected. Solimeo (2009) also draws out tensions when using discourses of ageing to account for PD’s lived experience, with PD both accelerating the physiological experience of ageing while also obscuring the natural ageing process, creating confusion regarding the boundaries between PD pathology and typical bodily ageing. Such studies therefore demonstrate the importance of exploring gender and age relations and their intersection in PD.

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

Methods

This paper reports findings from a project exploring men’s experiences of living with PD (ANONYMISED REF 2013). Thirty interviews were carried out with 15 men in 2011-2012. Participants were identified from a sub-sample of 100 men taking part in a clinical study investigating mood disorders in PD (ANONYMISED REF 2011). Participants attended outpatient PD, geriatric and movement disorder clinics in North West England and North Wales. A maximum diversity sampling approach drew on clinical research data to capture as wide a range of PD symptomology as possible, without reliance on a convenience sample. The sample was stratified according to age, PD severity, PD duration, and
The presence of motor and non-motor symptoms (table 1). Ethical approval was given by NHS South Manchester Research Ethics Committee (MREC number ANONYMISED).

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>PD Severity (Hoehn &amp; Yahr*)</th>
<th>PD Duration (years)</th>
<th>PD Motor symptoms (UPDRS**)</th>
<th>PD Non motor symptoms (GMS***, self-report)</th>
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<tr>
<td>Bob</td>
<td>80</td>
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<td>Depression</td>
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<td>Anxiety, Depression, Impulse control disorder. Hallucinations</td>
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<td>Anxiety, depression, Impulse control disorder. Hallucinations. Incontinence</td>
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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)

The average age of the sample was 71 (range 53-83). The majority of the men were in older age, defined here as being over the age of retirement. In addition three were aged 80 or over. Four of the men were in middle age, defined here as the ages between 45 and 65, with all four men being in their fifties or sixties. Two men were still in employment; the rest had retired or left work due to ill health. Six had been employed in manual or skilled technical occupations, while nine were middle class professionals. All of the men in this sample self defined as heterosexual.
The study adopted a phenomenological approach using narrative methods (Mishler 1986; Riessman 1993). Drawing on Wengraf’s (2001) biographical narrative interview methodology each man took part in an initial narrative interview followed by a semi-structured interview which further investigated narrative themes. Interviews lasted 1-4 hours and were conducted by the first author. Follow up interviews took place 1-3 months later after an initial analysis of narrative interviews. Interviews were audio recorded and transcribed verbatim by the first author. All participants were given the opportunity to comment on their transcripts, with two men doing so. Analysis was carried out by the first author with regular discussion with the second author. Taking as a starting point the idea that PD disrupts a normative ‘taken-for-granted or ‘absent’ embodiment (Leder 1990), the study explored men’s stories about living with PD and how gender and ageing were ‘emplotted’ within these stories (Mattingly 1998). Narratives were organised into themes using Watson’s (2000) male body schema. Transcripts were separated into individual stories relating to a specific activity or experience. These stories were then organised into themes such as, occupations, bodily sensations, emotions and moods. Themes were then organised in relation to pragmatic, visceral and experiential dimensions of embodiment. Findings are discussed in three sections. First we explore PD’s implications for a visceral embodiment which in turn are influenced by expectations of men’s ageing. We then discuss a pragmatic embodiment, in which men drew on masculine occupations to comprehend PD’s losses and reassert a masculine identity. Finally we discuss an experiential embodiment, where the emotions and sensations attached to PD’s symptoms led to the experience of a fluctuating bodily state which in turn threatened the accomplishment of masculinity.

Results

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

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

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

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

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

*Simon* When I’m in town I’ll stop at the village, in the road, and I’ll look, and I’ll look, and I’ll look again. Because you know that when you walk across the road sometimes you don’t walk as quickly as you want to, and you can’t actually make yourself hurry, so you make sure it’s safe to cross. Whereas I suppose if I was a typical elderly person, I would
just cross slowly and people would have to pull to a halt while I carried on crossing obliviously. So that’s me saying, it’s ageing me in that respect.

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

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

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

Roger

A common problem in PD, incontinence required intimate bodily management. Men frequently reported having to avoid any public spaces lacking public toilets, be watchful for the bodily sensations indicating the need to urinate/defecate, wear incontinence pads or return home should incontinence occur. Several men recalled episodes where they had been incontinent in public. Henry described an incidence of incontinence when buying a car far from home.
Henry I went to get out of the car and I was soaking wet. Absolutely soaking wet, my bladder had let loose (...). So now I’m in a position I’m soaking wet, I’m a long way from home, I’m fed up, so do I go home or what. So I rang them and I said “look I’ll tell you straight now, I’ve got Parkinson’s disease, I’ve just had a mishap in as much as my bladder’s just let go, I’m soaking wet, if you don’t want to see me I quite understand, but I can’t come back all this way again, so it’s now or never sort of thing”. (...) I can honestly say coming away from there they were very friendly people, (...) there were three men there that I was dealing with, two of them had got experience of Parkinson’s in the family, and they wanted to know more.

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

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 I’m fidgety, you think everybody sees it, you know. I think everybody’s looking at me, cos I know they are.

In contrast, , Henry preferred to ‘be up front’ about his incontinence when it occurred in public. For both Henry and Roger, incontinence was also mediated expectations of their bodies given their ages. For Henry, attributing incontinence to his PD was preferable to its association with older age. Indeed Henry claimed telling people that incontinence was a symptom of PD elicited a more sympathetic response, legitimising his experience as part of a disease process.
In contrast, Roger could not associate his incontinence on more conventional expectations of bodily ageing. For men such as Roger, illness could be used to explain their symptoms, however embarrassment or shame could continue to be felt even after such episodes. For Roger, his middle age meant ageing was not available as a means to explain his symptoms, while, explaining his incontinence as part of his illness still failed to account for the embarrassment or shame he felt. As a result, younger men were more likely to describe incontinence as a threat to their masculine status.

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

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

Int Does erectile dysfunction impact other aspects of your life?

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

Yet a number of older men described still having masculine desires, in many cases describing them as a natural part of their masculinity. Albert claimed he still had a libido, describing himself as being ‘a bit naughty’;
Albert well I do have a libido still. Most people do, even though they might not be able to perform, either with advancing age or advancing Parkinson's disease, the ability to perform decreases, but libido does not necessarily decrease. It doesn’t mean that you can actually do anything, raise to an err, you know, could have unfortunate consequences like fathering an unwanted child. You can’t do anything dramatic, but you may feel a little bit turned on, and be a bit naughty in the way you talk to people or, err, flirt with them for example.

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

Int. You mentioned that you’d been viewing pornography.

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

Int. Was that relatively recently?

Albert. It’s a substitute for the actual thing isn’t it.

Int. Is it recently you were doing that?

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

Albert’s wife prescribed very different meanings to this behaviour, describing his increasing libido as a distressing and out of character change in his behaviour she had raised with his doctors – a potential form of hypersexuality. The acts and feeling associated with sex could be understood as an expression of a stereotypical heterosexual masculinity, something lost naturally as men aged, an ‘old man’s hobby’, no longer appropriate in older age and therefore worthy of scorn, a deviant behaviour potentially distressing for the individual and those around them or finally a part of their illness to be monitored and treated.
In contrast men in middle age were more likely to describe sexual difficulties as an overt threat to their masculine status. Roger also worried about his declining libido;

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

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

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

Unwilling to resign himself to widowhood, Simon also worried if he would be able to attract another partner. Simon and Roger more closely aligned their difficulties with what they expected to be experienced by men 20-30 years their senior, both in terms of sex and more widely regarding their use of the physical body;
Simon: many other people in my situation are seventy, seventy five or older, got arthritic fingers or have too bad the tremor to deal with it. It must be hell. And I think what’s it going to be like for me in those days, when its hell for me now.

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

**PD and a pragmatic masculine embodiment**

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

Tony. Err, just, I haven’t the energy to do heavy work. Gardening, or working on the car. If there’s digging I can only do it for about half an hour and then I come in and I do whatever I’m doing, have a read or whatever, and if I feel like it I go out and do a bit more.

But I mean I’ve managed to do some quite heavy things. Once I get going, I’m not too bad, but it depends on the day.
Men’s accounts of PD frequently focused on its consequences for men’s work, defined through tasks including DIY or gardening, skilled technical work such as car maintenance, electrical rewiring or plumbing, or sports and hobbies like golf, bowls or rambling. Lacking strength and stamina, tasks such as lifting, carrying or digging became more difficult. Tremor restricted dextrous, skilful or detailed work, while fatigue left men struggling to keep up in their activities with other men. But importantly, when describing their difficulties men also tried to show what they could still do;

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

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

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

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

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

Ian. (becomes tearful). But it’s the physical demand of doing things that I can’t cope with. Things that you wouldn’t give a second thought to when you were fit, but now I have to think, how can I get round this, and how can I get round the other, and how can I do this, and how can I do that, I’ve got to be thinking all the time, to work out solutions, and 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 and off and on and off and on and off and I can’t get it to work at all.

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

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

**PD and an experiential embodiment**

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

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

The body itself increasingly had to be thought about, instructed and managed. Peter found himself having to pay attention to his hand as it picked up a cup, rather than to the cup itself. Rather than simply and unconsciously interacting with the various objects in the world, men increasingly had to think about the body, requiring both thought and concentration if they were to use it in the manner they wanted to. For many men, the body increasingly presented itself to their consciousness as an object, in many cases explicitly separate to themselves. Thoughts and memories were also affected, making men feel increasingly out of place as memories were forgotten or took longer to be recalled, or as conversations needed greater concentration and effort. Hugh struggled to keep up social contact with his family or friends:
Hugh: You are in conversation with somebody, and all of a sudden you’ve forgotten the name completely. It could be somebody well known, who you’ve worked with, and you just can’t. I go through the alphabet sometimes trying to memorise names. (…) It’s unpredictable, if you start a conversation and half way through, ‘oh what’s he talking about’, it’s gone from your mind. It happens quite often, especially when you are in company. It’s embarrassing that.

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

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

Men frequently described experiencing sudden changes in body sensations after taking medications, what Hugh described as ‘returning back to the planet’ or David called ‘kicking in’. During these periods, what have been called ‘on’ states within PD’s routine therapy, PD’s physical symptoms subsided; for example tremor could disappear while muscular stiffness also reduced, allowing the body to move more freely (Matson 2002). These physical benefits were also accompanied by other sensations. The body seemed to relax, for example being described as losing a heavy weight or feeling ‘good’ or ‘free’. Several men described feeling a ‘boost’, in which they moved and felt much quicker than before. On states were usually pleasant, but as PD progressed, larger doses were required in order to gain the
same therapeutic benefit. As PD worsened and the doses needed to promote an on state grew bodies
also began to move ‘too much’; exemplified by by dyskinesia’s or tics, jerks and other involuntary
movements. Alongside dyskinesia, during on states a few men also described, what Hugh called
feeling ‘hyperactive’;

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

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

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

Other men faced similar problems; Tom found himself ‘flittering’, unable to focus on any one thing
and struggling to complete his daily tasks. Henry and Roger wanted to spend money unnecessarily
while Hugh had gambled profusely, losing large amounts of money. For several men these experiences
were distressing, leading them to seek assistance from their medical practitioners. Yet in practice
beyond reducing the frequency or strength of medications there was little the medical staff treating
them could do to assist them with these problems. In such cases men either had to put up with them
using what Hugh called ‘mind over matter’ or reduce their medication dosages, potentially reducing such experiences occurring but at the same time worsening their motor symptoms.

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

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

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

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

In off periods bodies suddenly felt heavy, empty of energy and unable to fulfil simple tasks. Almost all movement ceased, while thinking slowed to a crawl. Once started all Hugh could do was wait out an
off period, taking a ‘booster’ medication in the hope of speeding its passing. For those experiencing them life increasingly had to be planned around off states, for example men curtailing any activities if they felt the tell-tale sensations indicating the start of an off period.

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

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

For Roger, masculinity became an increasingly visible performance as he struggled to ‘pass himself off’ as the person he once was. The significance of an experiential embodiment in PD lay in its increasingly fluctuating bodily experience. PD’s symptoms led to numerous, changes in the body while, PD’s drug therapy, although bringing numerous benefits in practice themselves led to men experiencing a balancing act between visceral and sensory embodiments. Together these experiences posed continued challenges to the experience of a taken for granted, habitual masculine body. Whether pleasant or detrimental the experiences associated with fluctuations between ‘on’ and ‘off states’ each distanced men from the taken-for-grantedness of embodied good health. These, and the
wider problems associated with PD could therefore put men’s bodies at odds with what were accomplish idealised or hegemonic forms of masculinity.

Discussion

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

Gender and age relations also intersected within men’s embodiment, together influencing how men made sense of their changing bodily experiences. Masculine bodily norms associated with youth and early middle age such as strength, stamina, and the taken-for-grantedness of intimate bodily functions remained important to men regardless of age. However older and younger men engaged with these norms from differing embodied and ageing standpoints. Cultural discourses of ageing and in particular of an age-based decline were drawn on as a means of comprehending many of the various bodily changes occurring in PD. These discourses and the expectations based on them however also served to maintain and even reassert age appropriate forms of masculinity (Emslie et al 2006; Spector Mersel 2006). By comprehending and accepting PD as part of the ageing process, PD could be considered as Faircloth et al (2004) terms a ‘normal crisis’; part of the natural trajectory of older age rather than an
illness event inherently disruptive to personal biography. In doing so, older men could avoid or resist narratives of illness while also maintaining a masculine biographical self; for example by demonstrating the virtues of bravery, humour, stoicism and struggle in the face of their growing physical limitations. In contrast, for men with PD in middle and early old age, the expected declines of older age provided a closer opportunity to comprehend PD's lived experience than their expectations of illness. However PD meant these declines were all now happening much earlier in life than they should (Singer 1974; Solimeo 2009). Men with PD in middle age struggled to draw upon a shared narrative of bodily ageing in ways which could successfully account for their difficulties. The abnormality of bodily decline relative to ages left men in middle age unable to meet embodied expectations of given their stage in the lifecourse, while simultaneously lacking the discourses of acceptable male ageing that older men could use to account for their declining bodily states (Calasanti & King 2005).

Importantly, the progressive nature of PD, alongside the sensitive nature of some PD symptoms meant that PD had ongoing, continual and unstable effects both on men’s bodies and men’s continuing embodiment. As symptoms arose, as abilities declined, and as bodies changed in the way they responded to medications, the changes occurring in men’s bodies required a frequent re-negotiation and reconstruction of identity (Bury 1982; Faircloth et al 2004). Eventually PD could cease to be a ‘normal crisis’, as it overtook men’s ability to either reassert their masculinity or to mobilise discourses of age-based decline in order to explain their difficulties. Men could make light of tremor as ‘its just the parkies’, but symptoms such as incontinence, off periods or hypersexuality challenged ideals about (men’s) bodies and so could not so easily be explained away. As such symptoms developed, men across the lifecourse increasingly struggled to locate PD within their expectations of physiological decline for men of their ages; a, as abilities and activities were lost faster than they could compensate for them, or as they lost control over the intimate bodily functions. Age and gender therefore intersected shaping both how the physiological effects of PD came to be known, and determining the
options available to men when responding to these effects (Solimeo 2008). Studies of masculinity and health should therefore explore how masculinities both challenge and sustain men’s identities, the ongoing nature of this process, and how this process changes as progressive illnesses develop and as men age (Emslie et al 2006; Robertson et al 2010).

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

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

- Bramley, N. and Eatough, V. (2005) the experience of living with Parkinson’s Disease: An interpretive phenomenological analysis case study, *Psychology and Health*, 20, 2, 223-235
- ANONYMISED REFERENCE
- Calasanti, T. and King, N. (2005) firming the floppy penis: age, class and gender relations in the lives of old men, *Men and Masculinities*, 8, 1, 3-23


• ANONYMISED REFERENCE


• Hurd Clarke, L., Bennett, E. (2013) ‘You learn to live with all the things that are wrong with you’; gender and the experience of multiple chronic conditions in later life *Ageing and Society* 33: 2 342-360


• King, N., Calasanti, T (2013) Men’s aging amidst intersecting relations of inequality *Sociology Compass* 7: 9 699-710


• Parkinson’s UK. (2011) Parkinson’s Audit 2010 Available at http://www.parkinsons.org.uk/PDF/Parkinsons_Audit_Report_2010.PDF (last accessed 31/1/2012)

• Playfer, J. (2007) Ageing and Parkinson’s Disease, *Practical Neurology*, 7, 1, 4-5


• McVittie, C., Willock, J (2006) “you can’t fight windmills”: how older men do health, ill health and masculinities *Qualitative Health Research* 16: 6 788-801


• Williams, S. (2006) Medical Sociology and the Biological body: where are we now and where do we go from here?, *Health*, 10, 1, 5-30