



'Signposts on the journey'; medication adherence and the lived body in men with Parkinson's disease



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ABSTRACT

Adherence to medication has been identified as a key issue in the treatment of many chronic illnesses, however such a perspective fails to account for the lived experience of medication usage and its effects on the body as lived. Parkinson's Disease, a neurological disease predominantly affecting movement and mobility, and which is treated via a wide range of medications provides a useful opportunity to explore experiences of medication usage in chronic illness. Reporting on findings of a study exploring men's experience of living with Parkinson's Disease, this paper adopts a lived body perspective to explore lived experiences of medication usage and adherence in PD. Findings are reported from 30 narrative in depth interviews with 15 men of various ages living with Parkinson's disease of mild to severe intensity. Findings first discuss PD's effects on men's sense of the lived body, in which a fluctuating embodiment is linked to medication regimes and their bodily effects. Second, as PD disrupts the body's place with the everyday and habitual experience of lived time, medication regimens come to place new structures upon the men's everyday experience of time. Finally, the paper explores the role medications play in men's attempts to create and sustain narratives for the individual progression of their illness, and how these narratives differ from clinical narratives associated with PD's treatment. This paper concludes by discussing debates around adherence to medication within the treatment of PD and the need to consider lived experience of medication usage and their effects at the level of the lived body.

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1. Introduction

As the demands of chronic illnesses rise within western societies, increasing attention is being paid to the effects of medication usage and the social contexts in which medications are administered (Adams et al., 1997; Buus, 2014). Given the increasing burden medication prescribing places upon health care systems, ensuring both efficacious clinical responses to medication regimes and efficient and cost effective prescribing for health care systems is growing in importance. Within health services research adherence, or how far patients engage with practitioners in managing their own medication regimens has grown in favour over compliance, or the extent to which patients use medications as prescribed. This change has been positioned as a result of greater consideration within adherence to the notions of dialogue and partnership existing between clinician and patient within the clinical encounter (Conrad, 1985; Pound et al., 2005; Drey et al., 2012; Daley et al., 2012, 2015).

Parkinson's Disease (PD), a chronic and progressive neurological illness whose symptoms affect movement and mobility gives us an opportunity to explore the relevance of the lived body to medication adherence. Although no treatments are available which can cure PD, a number of medications can alleviate its symptoms (Jankovic, 2008). Seeking to either replace or preserve levels of the neurotransmitter dopamine, these medications can alleviate PD's symptoms for several years. However a number of well documented problems also accompany PD medication usage (Drey et al., 2012; Haahr et al., 2010; Gibson et al., 2013). As with many chronic illnesses, adherence to PD medications is low (Grosset et al., 2009; Drey et al., 2012; Daley et al., 2012). Kulkani et al. (2008) record 60–70% of PD patients failing to adhere to PD medication regimes over a 5 year period, with only 3% achieving full adherence. Drey et al. (2012) identify a number of behaviours among people with PD to explain this non adherence, such as forgetting to take medications as prescribed or at the correct times. The benefits PD's medications can bring are also time limited, with the beneficial effects of levodopa, PD's most common drug therapy subsiding after 4–6 years (Brooks, 2008). Typically the response is then to

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increase dosage and add further medications to the mix, meaning that as their illness worsens patients will take multiple medications in repeated doses (Daley et al., 2012). These increases typically lead to a range of side effects caused by the often massive doses of levodopa now needed to bring therapeutic benefit. Such effects include hallucinations (Gibson et al., 2013), mood disorders (Brown et al., 2011), dyskinesia or peak dose involuntary movements, and wearing off; the sudden and unpredictable loss of motor functioning (Matson, 2002; Solimeo, 2009; Moore et al., 2014).

Although useful, compliance and adherence each regard patient's ability to follow their medication regimes as a 'problem' to be alleviated. Within a clinical and neurological model of PD therapy, problems of adherence are framed as a recalcitrant behaviour among patients and a problem for practitioners, solved for example through better education (Drey et al., 2012; Daley et al., 2012). In contrast, a lived body perspective situates bodies as having a physiological reality while also being constituted through social relations explores medication adherence at the level of the body-self (Pickard and Rogers, 2012). Within such an approach medication adherence can be understood in terms of the consequences medications may have for an embodied self and its position in the world. While PD research has been dominated by the medical model, a few studies have adopted lived body perspectives in PD. In an idiographic account of a woman in middle age living with PD, Bramley and Eatough (2005) and Solimeo (2009) each describe PD as an unstable bodily experience characterised by 'flux and unrest', in which bodies could fluctuate seemingly without cause. Haahr et al. (2010, 2011) & Hariz et al. (2011) explore Deep Brain Stimulation (DBS), a neurosurgical procedure used when PD symptoms can no longer be adequately treated by medications. DBS is initially experienced as a 'miracle' allowing people with PD to live a life not experienced since before their diagnosis, but which once again worsens as PD continues to progress. Yet no studies have used a lived body perspective to explore experiences of PD's drug therapy. Drawing upon phenomenological perspectives concerning the lived body and the lifeworld, this paper therefore explores men's experiences of taking medications used to treat PD, the implications adherence to PD medication regimes have as experienced through the lived body, and the meanings given to PD medications and their use.

2. Methods

This paper draws on data from a project exploring men's experiences of living with PD (Gibson, 2013). Thirty interviews were conducted with fifteen men with PD who were participating in a clinical study examining the prevalence of mood disorders in PD (Brown et al., 2011). Participants were attending movement disorder, geriatric medicine or PD clinics located in the North West England and North Wales regions of the United Kingdom. A maximum diversity sample of participants were identified using clinical rating instruments collected during the clinical study. The sample was stratified by age, socio economic status, length of time with PD, PD severity (Hoehn and Yahr, 1962), motor and non-motor symptoms and presence of medication side effects (Table 1). Ethical approval was given by NHS South Manchester Research Ethics Committee (MREC number 08/H1003/131).

The study adopted a qualitative, phenomenological methodology concerned with the lifeworld and its experience through the lived body (Merleau Ponty, 1962; Toombs, 2002; Pickard and Rogers, 2012). We experience the lifeworld, or the taken-for-granted, mundane horizon of everyday life, through the lived body; the body as it is immediately experienced (Toombs, 1993). However in what Leder (1990) terms 'dys-appearance', illness brings the body's position in the world into relief as its ability to

engage in practices, roles and relationships in everyday life declines (Pickard and Rogers, 2012). In many illnesses this experience may be transient, however in chronic illnesses such as PD these experiences may become permanent, irrevocably changing the lifeworld (Leder, 1984; Habermann, 1996; Sunvisson et al., 2009). In addition, while many chronic illnesses including PD have therapies which can reduce the impact of symptoms, these treatments cannot return the body to pre-illness health, and may also bring about their own side effects. As a result, the return to the absent body of good health may not be possible, indeed further disruptions may be experienced in addition to those caused by the underlying illness. A lived body perspective therefore provides a means to explore the benefits and consequences of PD's treatment practices as they are lived.

Interviews were organised using Wengraf's (2001) biographic narrative interview methodology. All participants took part in an initial narrative interview, in which participants were asked the following question designed to elicit narrative responses; *"In your own words, I would like you tell me about your general experiences of living with Parkinson's disease, and the problems that it has caused for you"*. Follow up questions which encouraged further narrative responses were also asked (e.g. *could you tell me what happened then?*). A second, semi structured interview took place 1–3 months later, with questions being tailored to the themes emerging from the stories within participants earlier interviews. Interviews lasted 1–4 h, averaging 2 h. All participants were asked to give informed consent by completing a consent form prior to interview. Participants were also given the opportunity to re-affirm consent prior to taking part in the second, semi-structured interview. All interviews were recorded and transcribed by the first author. Transcripts were analysed using a lived body perspective and a form of narrative analysis informed by Mishler (1986) and Riessman (1993). Interviews were separated into individual stories relating to a phenomena. Using Riessman's (1993) narrative structure, stories were then organised according to their abstract, complicating action, evaluation, resolution and coda. Not all stories contained each of these elements (in particular lacking resolutions or coda's where narrators stories tailed off, or where narrators switched to another story) however where possible each story element was organised according to the above structure. Analysis of narratives then informed questions asked in subsequent semi structured interviews, which sought to seek further insights about the men's stories. Analysis focused on the content of men's stories, with subsequent information collected in later interviews used to provide further contextual information about stories. This analysis focuses on a sub set of data detailing men's accounts of medication, its effects on the lived body and for adherence to medication and medication regimes.

3. Results

3.1. Medications and the lived body; a fluctuating experience

Unsurprisingly PD led to a range of bodily effects, including PD's cardinal motor symptoms (tremor, muscular stiffness and slowed movements) and non motor symptoms such as depression, anxiety, hallucinations, sexual difficulties and continence problems (Jankovic, 2008). All of the men were prescribed PD medications to control these symptoms. Medications either restored lost dopamine or preserved dopamine remaining in the brain, and led to at least some improvement to physical functioning. Yet these improvements did not return the body to an 'absent' bodily state characterising good health. Instead they were accompanied by often vivid bodily sensations, what David called 'kicking in';

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