Men's Experiences of Living with Parkinson's Disease

Grant Gibson
Newcastle University, UK
grant.gibson@ncl.ac.uk

ABSTRACT
The goal of this thesis is to explore men's experiences of living with Parkinson's Disease, a progressive neurological disorder predominantly affecting men in older age. Research into PD has been predominantly informed by a biomedical, neurological model. Although bringing significant benefit to PD's treatment, this approach fails to adequately consider the question of PD's lived experience, leading to major gaps in our knowledge of the condition and its effects on sufferer's lives. In addition, although making up the majority of sufferers, the specific needs of older men with PD have been neglected within wider research into PD. Using a phenomenological methodology concerned with men's experience of the lifeworld, and how this experience is influenced by gender and ageing, this study used narrative interviews combined with a photographic elicitation approach to ascertain the lived experiences of 15 men, from a number of different areas and of differing ages.

The findings of this thesis indicate that PD is more than simply a movement disorder. Instead it should be understood as a condition which disrupts the unity of the body, self and world. PD brings about particular challenges to men's experience of the lived body and lived time, distancing them from a shared experience of the lifeworld. Men also found ways to try and cope with their PD, but these approaches had to continually change as men moved through the illness. Finally, men's lived experience was intertwined with ageing and masculinity. PD posed a threat to men's masculine status; however men could also use masculinity as a resource to understand PD's various effects on their lives. How well men could respond to these changes had key implications for their continued well-being and quality of life, therefore giving insights into how future PD services can be improved.

This thesis concludes by making recommendations for the development of person and gender sensitive services in PD. These include paying greater attention to PD's lived experience and the stories men tell of their illness; engaging with the problems men identify that PD causes in their lives; and the greater provision of forms of information and psychosocial support which recognises all of PD's effects; including non-motor symptoms, psychosocial consequences and medication induced side effects.

Keywords: Parkinson's Disease; Embodiment; Phenomenology; Narrative; Masculinity; Ageing