Perceptions of cause and control in people with Parkinson’s disease

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Theories of self-regulation suggest that illness beliefs can impact on wellbeing and adaptation and also influence a wide range of health related behaviours. This work is concerned with two particular illness beliefs in people with Parkinson’s disease (PD), namely perceptions of cause and perceptions of control.

The first section presents a narrative synthesis of the quantitative research on the demographic, clinical and psychological correlates of control in PD and two other chronic motor illnesses; multiple sclerosis (MS) and motor neurone disease (MND). Age, gender and disease duration were not found to be consistently related to control. However perceptions of control were associated with some measures of disease stage/disability. Furthermore, increased perception of certain types of control, particularly life control and adaptation to disease impact, was also associated with wellbeing. The results were dominated by the large number of MS studies but appeared largely applicable to people with PD, however applicability to MND was less clear.

Whilst quantitative studies advance understanding of illness beliefs, they also have limitations as they do not permit understanding of the context in which beliefs are formed and or the meaning or purpose of the beliefs for individuals. Thus a qualitative investigation was undertaken of how perceptions of cause and control arise in the everyday lives of people with PD. Interpretative phenomenological analysis of data gathered by semi-structured interviews resulted in a number of relevant themes, of which three were selected for presentation. These themes examined 1) different types of causal attribution; 2) perceptions of control of symptoms by medication; and 3) the secondary control process of adaptation with particular
focus on acceptance and denial. The links between cause and control were not universal but rather occurred in subtle individual ways. A flexible and responsive social and healthcare system is required to support individuals appropriately. Further research is needed on suitable psychological interventions to enhance control.

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