

**PERCEIVED CONTROL IN THE
EVERYDAY OCCUPATIONAL ROLES
OF PEOPLE WITH PARKINSON'S
DISEASE AND THEIR PARTNERS**

By

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Thesis Abstract

People with a chronic illness such as Parkinson's disease often live in the community for many years while the illness becomes progressively more debilitating. Little is known about how such people control the impact the disease has upon their various roles in life. This study employed naturalistic qualitative research methods to investigate how people with Parkinson's disease and their partners continue to actively participate as members of their social community. Using in-depth semi-structured, focused interviews, participants with Parkinson's disease and their partners were asked to name and describe roles that occupied their daily activity. They were asked about their most significant occupational roles, what they *did* in these roles, the *knowledge* or strategies they employed to deal with barriers to occupational role performance, and the *personal meaning* such roles held.

Four basic themes evolved from the data: the impact of the disease on occupational role performance, or 'doing', secondary personal limitations to occupational role performance, secondary social limitations to occupational role performance and cumulative barriers to occupational role performance. Loss of control over choice and manner of engagement in occupational roles was a significant element of all four themes. Sense of self and sense of social fit were identified as major elements that informed participants' perceptions of control.

Participants described a range of diverse responses that they used to actively restore personal control of occupational performance in the face of degenerative illness. Learning new coping styles appeared to be underpinned by a personal set of rules or 'blueprint', despite professional input. This blueprint was actualised through a problem identification, problem solving and active engagement cycle that was termed *a cycle of control*. A conceptual model of a cycle of control was proposed as the final stage of the research. The model represented a way of describing how participants acted to restore a sense of personal control once a specific barrier to occupational role performance had been perceived.

The findings of this study support the notion that people with chronic illness such as Parkinson's disease, are active and knowledgeable participants in health care, and have occupational histories and experiences that they harness when dealing with barriers to performance. Moreover, the findings demonstrate that people with chronic illness work in tandem with significant role partners to constantly maintain the valued partnership in meaningful occupational roles as the disease progresses. A greater understanding of how

people with chronic illness and their partners strive to maintain a sense of personal control can enable occupational therapists to work effectively as ancillary partners in care. A greater understanding of the way in which role partners work together to maintain occupational integrity in their lives would be central to assessment and intervention for community programs for people with chronic illness.

Declaration

I certify that this thesis has not been submitted for a higher degree to any other University or Institution.

I certify that the work in this thesis is the work of the author, except where acknowledged.

Anne Hillman

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