A5-6: The Illness Experience of Persons with Parkinson's Disease

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Abstract:
Introduction: Parkinson’s disease is a chronic, progressive, neurodegenerative disorder with no known cause or promising cure. While substantial information is known about the pathophysiology of Parkinson’s disease, little is known about the illness experience of persons living with the disease. The purpose of this study was to understand how persons with Parkinson’s disease construct their illness experience and manage living with their illness on a daily basis.

Method(s): A qualitative study with an ethnographic approach employed the strategies of participant observations and fieldwork. Field data were generated from a two year exposure to two Parkinson’s disease support groups in east Texas. Open-ended semi-structured interviews with seven men and seven women with Parkinson’s disease were also conducted. These data were combined and analyzed using thematic analysis.

Results: The illness experience is described through the metaphor “Sailing the Sea in The Eye of the Storm.” This metaphor served as the overarching theme that covered the two interacting content themes of the voyage of Daily Negotiations in the Midst of Uncertainty and Reconstruction of the Self with Parkinson’s Disease. Daily negotiations incorporated navigating daily activities with the uncertainty of both the progression and daily vicissitudes of the disease. Participants described their symptoms as progressive imprisonment that interfered with daily activities. The progressive nature of the disease required the participants to reconstruct their perceptions of themselves. Reconstructing the self involved the paradoxical balancing of preserving the self while simultaneously releasing aspects of the former self to reconstruct the self with Parkinson’s disease.
Discussion & Conclusions: This qualitative study illuminated the struggle of persons in dealing with the uncertainties and fluctuations of Parkinson’s disease and the process of reconstructing their perceptions of themselves. The meaning and reconstruction of the illness experience expressed by participants will inform understanding beyond the disease itself to the illness experience that these participants must deal with on a daily basis.

Abstract History:
This abstract has been published or accepted for publication.

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