PhD Thesis of Nursing

Exploring of Self-Care Process in People
With Parkinson's Disease: Developing a Theoretical Model

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Abstract

Background: Parkinson's disease is a degenerative disorder of the central nervous system. Chronic diseases such as Parkinson impact over all aspects of economic, financial, social, emotional and individual, family and community. However, to date, many developments in the diagnosis, treatment and rehabilitation of people with Parkinson's have been occurred however there is not clear view of self-care manner in these patients. Thus, further understanding of the problems, concerns and challenges in the care of these patients can be one of the contemporary research priorities. This study aimed to explore the process of self-care in patients with Parkinson's disease.

Methods: This Study was an exploratory qualitative design and carried out using Grounded theory methodology. Participants were selected from the neurological clinic. Needed data were collected via semi-structured in-depth interviews and field notes. We interviewed with 12 people with parkinson's disease and 4 family caregivers. Peoples who have different experiences of self- care in terms of age, sex, marital status, education, socio - economic status, employment status, duration and severity of disease were participated in study so theoretical saturation was achieved. The most interviews were conducted in private home of participants or one of their family members and in nursing homes, respectively. Abbreviated Mental Test with a score of 7 or higher were used for evaluation and screening of people with cognitive impairment. We used from Index of Hohen & Yahr to assess the severity and stage of parknison's disease. We used the MAXQDA Version 10 in order to manage and organize of data. Process of collecting and analyzing data were concurrently performed. Analyzing data was carried out with the Corbin and Strauss (2008) approach. For data analysis, we also used the analytical tools such as asking questions, making comparison (constant comparison and theoretical comparison) and the different meanings of a word.

Findings: Concepts of study were identified with using a micro analysis and follow general analysis. 'Progressive disability', 'Financial Burden of Disease', 'Self change', 'Mental Turbulence', 'Disrupted Social Connectedness' and 'Family Background' were referred to the context. One of the essential steps in analyzing data for context was to identify the main concern of Peoples with Parkinson's disease. We identified 'fear of becoming crippled in
future' as a main concern in these Peoples. This concern was created with the effect of Parkinson's disease on physical, emotional, mental, and social aspects. After identifying the strategies that were used by the patients in response to context ('Independency', 'Spiritual Care', 'Informed Self-Care' and 'Seeking Treatment'), we sought to explore the most important strategy/ process, in peoples with Parkinson's disease in self-care. 'Striving for take independent care' was the most important process in these patients. 'The fear of becoming crippled: Striving for take independent care' was determined as main phenomen.

**Discussion:** The results of this study showed that the process of self-care in peoples with Parkinson’s disease depends on context and according to the severity of signs and symptoms could be varied. The findings also showed that demographic, familial and social factors have important roles in self-care process of people with Parkinson's disease. These factors occasionally facilitate the self-care process, and sometimes made it difficult. With understanding these factors, health care providers can support people with Parkinson's disease in achieving maintain independence in self-care. In addition, attention to self-care behaviors with focus on person as self-care agent can considerably increase control and management of life. Slow down disease progression, reducing the number of admissions, reducing refer of patients to medical centers and clinics, reducing the financial burden of the disease and increase life satisfaction can be the consequence of performing self-care behaviors. On the other hand, the results of this study can be used in the formulation of policy and the standards of care in our country with providing the important concepts and a basic knowledge of the process of care of peoples with Parkinson's disease.

**Key words:** Parkinson's disease, Caring, Self-Care, Qualitative study, Grounded Theory