

Emergence and evolution of social self-management of Parkinsons disease

<https://neurodegenerationresearch.eu/survey/emergence-and-evolution-of-social-self-management-of-parkinsons-disease/>

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Contact information of lead PI Country

USA

Title of project or programme

Emergence and evolution of social self-management of Parkinsons disease

Source of funding information

NIH (NINDS)

Total sum awarded (Euro)

€ 1,972,191.74

Start date of award

01/04/2013

Total duration of award in years

2

The project/programme is most relevant to:

Parkinson's disease & PD-related disorders

Keywords

Self Management, Parkinson Disease, Evolution, social, Neurological Nursing

Research Abstract

DESCRIPTION (provided by applicant): Parkinson's disease (PD), one of the most common age-related neurodegenerative disorders, affects facial, vocal and trunk muscles. As this

progressive decline occurs, an expressive mask descends, limiting the person's ability to communicate emotions and intentions to others, which may give the impression that the person is cold, asocial or apathetic. Thus, people with PD are living longer and residing in their homes longer, the burden of care-giving is unmitigated by the social and emotional rewards provided by an expressive individual. While this disability has been discussed in the literature, relatively little is known about how adults living with a chronic physical disease such as PD manage their social lives and how an inability to be emotionally expressive can affect social connections. Because social networks have been shown to be crucial to the overall well-being of people living with chronic diseases, research on how expressive capacity affects life trajectories and overall health is critically needed. The overall objective of this project is to understand the emergence and evolution of social self-management trajectories of people living with PD, and this work has the potential to significantly advance PD research and evidence-based neurological nursing and rehabilitation. We will test the central hypothesis that PD expressive capacity predicts systematic change in the pattern of social self-management of PD and quality of life outcomes. The Specific Aims of this three-year longitudinal study of 120 patients with PD and a maximum of 120 care partners are: 1) Characterize social self-management trajectories of individuals with PD over a three-year period; 2) Estimate the degree to which expressive nonverbal capacity predicts the social self-management trajectory; and 3) Determine the moderating effect of gender on the association between expressive capacity and change in social self-management. Over the three-year project period, we will assess patients with PD and a care partner 14 times each to examine such factors as social participation and management of social activities; social network; and social comfort, general health and well-being. Descriptive analyses will be performed on the total sample and on meaningful demographic and clinical subgroups. This study is designed to have sufficient power to detect changes over time and to detect differences in gender. Our contribution is significant because it will provide evidence to guide the development of interventions aimed at supporting social integration of people living with PD, thus leading to improved overall health. The proposed work is innovative because, to the best of our knowledge, it is the first to focus on the novel construct of social self-management and does so in a manner that reflects the daily lived experience of PD. Further, we go beyond descriptive evidence to rigorously test hypotheses regarding factors known to contribute to social stigmatization, expressive capacity and gender.

Lay Summary

PUBLIC HEALTH RELEVANCE: Parkinson's disease (PD) affects 1% to 2% of the US population over age 60, and its prevalence is increasing as the population ages. The proposed research will establish the natural evolution of the social lives of people with Parkinson's disease and their families and its relationship to health outcomes, and thus has the potential to significantly advance Parkinson's disease research and evidence-based neurological nursing and rehabilitation. The project develops the new construct of social self-management of chronic disease and results will inform the development of new interventions aimed at supporting social integration and preventing isolation and loneliness in people living with Parkinson's disease.

Further information available at:

Types:

Investments > €500k

Member States:

United States of America

Diseases:

Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

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