Neuroscience and Biobehavioral Reviews 61 (2016) 26–34

Contents lists available at ScienceDirect

Neuroscience and Biobehavioral Reviews

journal homepage: www.elsevier.com/locate/neubiorev

Review

Health-Related Quality of Life in patients with Parkinson's disease—A systematic review based on the ICF model

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ARTICLE INFO

Article history:
Received 5 June 2015
Received in revised form
20 November 2015
Accepted 21 November 2015
Available online 2 December 2015

Keywords:
Body function
International Classification of Functioning and Health
Parkinson's disease
Participation
Physical activity

ABSTRACT

We analyzed features associated with a reduction in Health-Related Quality of Life (HRQoL) in people with idiopathic Parkinson's disease (PD). As a new approach, features were embedded in the WHO framework for measuring health and disability, the ICF model. From 609 articles screened, 114 articles were included. Features aligned with the ICF's body functions and structures domain (BFS) were investigated more often than personal features, activities of daily living, environmental factors, and participation in societal roles (95, 42, 35, 29 and 14 times, respectively). The strongest associations were found for the relationships between HRQoL and "psychosocial functioning" from the participation domain and HRQoL, and "mobility limitations" from the activities domain. For the BFS, non-motor symptoms were more closely associated with reduced HRQoL than motor symptoms. In conclusion, this systematic review (i) provides entirely new insights in the association of HRQoL with PD features, (ii) shows an imbalance between most extensively investigated and most relevant features for HRQoL, and (iii) demonstrates the usefulness of the ICF model for such an approach.

Contents

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http://dx.doi.org/10.1016/j.neubiorev.2015.11.014
0149-7634/

1. Introduction

Parkinson's disease (PD) is a chronic, progressive neurodegenerative multisystem disorder. It can present with a wide variety of symptoms and signs (from now on referred to as features) that can affect Health-Related Quality of Life (HRQoL). HRQoL incorporates dimensions of physical, mental, social and role functioning, and can include abilities, relationships, perceptions, life satisfaction and well-being (Wood-Dauphinee, 1999). HRQoL is arguably one of the most important factors that influences therapeutic decisions for people with chronic diseases, and is often a primary outcome variable in clinical trials (Wood-Dauphinee, 1999; Deuschl et al., 2006; Schuepbach et al., 2013; Wenger et al., 1984). The interest in HRQoL research in PD has grown rapidly, with many studies published over the last decade. However, the definitions of HRQoL and the methods used to assess it vary, making studies difficult to compare without reference to a unifying theoretical framework.

In 2001, the World Health Organization (WHO) developed the International Classification of Functioning, disability and health (ICF) model, to conceptualise health and disability at individual and population levels. The ICF model is constructed around the following domains: body functions and structures, activities (of daily living), participation (in societal roles), personal features and environmental factors (Fig. 1). The ICF model poses that each of these domains has complex interactions with each other (WHO, 2006). The ICF model goes beyond the usual focus on a diagnosis, and incorporates medical and societal aspects of an individual's health condition. The ICF model has proven to be a useful tool to document difficulties PD patients experience on a personal, as well as community level (Raggi et al., 2011). As HRQoL incorporates a broad array of facets of life, the ICF model can be seen as an ideal framework to classify HRQoL in chronic diseases, such as PD.

Although some reviews of HRQoL in PD have been published (Den Oudsten et al., 2007; Dowding et al., 2006; Post et al., 2007; Soh et al., 2011), none have considered how HRQoL in people with PD varies across the different dimensions of the ICF.

This review presents a systematic and detailed analysis of PD-related features that have been investigated in relation to HRQoL, and assigns them to the above-mentioned five ICF domains (body functions and structures, activities, participation, personal features and environmental factors). The review also proposes a method for ranking the influence of investigated features in relation to HRQoL.

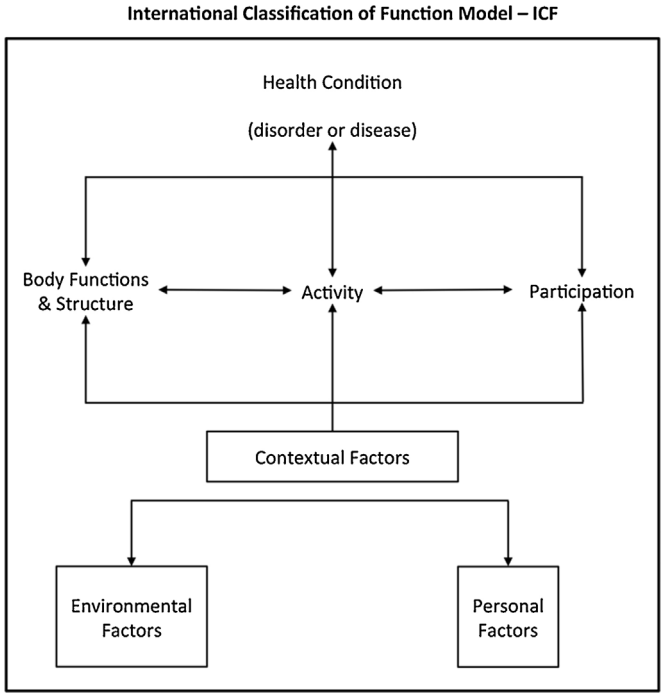

Fig. 1. The International Classification of Functioning and Health model, developed by the World Health Organisation, as a framework to assess health and disease/disabling conditions (WHO, 2006).

2. Methods

2.1. Search strategy and study selection

An electronic literature search was performed in January 2015, using the search terms "Parkinson's disease" (MeSH), "health-related quality of life", "patient reported outcome", "determinants", "factors", "predictors" and "variables". All available articles published between January 1, 1985 and December 31, 2014 were included. This search yielded a total of 1468 results which originated from: Pubmed (365), Medpilot (including Medline, Cochrane, and CCmed; 517), PsychInfo (175), and Web of Sciences (411).

Next to an electronic search, a targeted hand search was performed, which involved reference lists of articles identified through the electronic search, as well as reference lists from previously