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**Wherry, Sally-Anne ORCID: 0000-0002-2496-1178, Dugdale, Paul, Lueck, Christian J. and Das, Chandi P. (2015) Self-Management: Parkinson's as a Chronic Condition. In: Movement Disorder Society International Congress, 18/06/2015, San Diego.**

EPrint URI: <https://eprints.glos.ac.uk/id/eprint/6735>

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# Self-Management: Parkinson's as a Chronic Condition

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Movement Disorder Society International Congress, San Diego, 18 June 2015

## Setting

Parkinson's is cited as a chronic disease which is a "disease... of long duration and generally slow progression"<sup>1</sup>. The burden of chronic, neurodegenerative diseases, including Parkinson's, is a growing problem worldwide, and it is necessary to find ways to support People Living with Parkinson's (PlwP) and their carers world-wide.

## Objective

This poster presents the results of a systematic review of the existing literature relating to self-management in PlwP.

## Methods

The Cochrane Database of Systematic Reviews, PsycINFO, CINAHL and Embase were used to identify evidence such as randomised controlled trials and original literature, as well as evidence-based guidelines, evidence-based review articles and meta-analysis relevant to the topics reviewed. 3532 studies were found in total, of which 49 were appropriate for review. Selection was based on quality of evidence and relevance to the topic (table 1). Five studies were judged as meeting the inclusion criteria and included in the initial review. Data was extracted, summarised, coded and critiqued.

## Findings

Five studies<sup>2,3,4,5,6</sup> provided evidence related to the effectiveness of self-management (Table 1). Four of the studies demonstrated beneficial impact<sup>2,3,4,6</sup> but one study<sup>5</sup> showed negative impact, namely worsening in fatigue scores.

**Table 1: Systematic Review of Evidence of Self-Management Strategies in Neurological Diseases**

| Evidence Class | Author(s)                         | Date | Population   | Intervention                                   | Randomised              | Blinded | Outcome  |
|----------------|-----------------------------------|------|--|--|-------------------------|---------|--|
| II             | Tickle-Degnen et al. <sup>6</sup> | 2010 | Idiopathic Parkinson's                                 | Self-management rehab – increasing hours       | Y                       | Y       | Improved self-help efficacy  |
| II             | Lorig et al. <sup>4</sup>         | 2012 | One or more chronic conditions                         | Online chronic disease self-management program | N                       | N       | Improved health indicators and health behaviours. Reduced use of health services |
| III            | Ghahari et al. <sup>2</sup>       | 2012 | Multiple sclerosis, Parkinson's or post-polio syndrome | Fatigue self-management program                | Y                       | N       | Improved self-efficacy and satisfaction. Reduced stress.                         |
| IV             | Nelson et al. <sup>5</sup>        | 2011 | Parkinson's  | Chronic disease self-management program        | N                       | N       | Worsening in fatigue score   |
| IV             | Kennedy et al. <sup>6</sup>       | 2007 | Self-defined long-term condition                       | Chronic disease self-management program        | Pragmatic randomisation | N       | Improved self-efficacy and health status; reduced health service use             |

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## Emerging Themes

**Experience of illness:** Three areas emerged from the evidence as particularly impacting on self-management. Pain and fatigue was an area that was improved by CDSMP involvement<sup>3,2,5</sup>.

Deterioration and acceptance of loss of physical and mental function was a large issue for people living with the fluctuating nature of the disorder<sup>5</sup>. Depression was positively impacted by the CDSMP, with increased sense of self-efficacy and reduced stress levels<sup>5</sup>.

**Ways of coping:** Relaxation was a key theme throughout the literature, which responded positively to mindfulness exercises<sup>3,4</sup>. Self-tailoring was shown to be highly beneficial to participants, and was a particular focus for the young onset PlwP<sup>4</sup>.

**Use of Health Services:** Many of the studies found no impact on health service use, with only one<sup>4</sup> finding any reduction in emergency room visits. It was noted that the participants had appropriate use of health services at baseline but developed better collaborative relationships with their healthcare teams<sup>3</sup>.

**Self Efficacy:** Self-efficacy was measured in the majority of studies and found to be worthwhile in most<sup>6,4,3</sup>, with benefits sustained for one year<sup>4</sup>.

**Table 2: Demographics of cohorts**

| Author                            | Average Age | Gender F/M | Post-school education | Ethnic Background            | City / Rural  |
|-----------------------------------|-------------|------------|-----------------------|------------------------------|---------------|
| Tickle-Degnen et al. <sup>6</sup> | 66.3        | 30/68      | 54.3%                 | 96.6% Anglo (other unstated) | 100% / 0%     |
| Lorig et al. <sup>4</sup>         | 45          | 150/103    | 40.9%                 |                              | 0% / 100%     |
| Ghahari et al. <sup>2</sup>       | 50.25       | 81/18      | 42.1%                 | not stated                   | 60.6% / 39.4% |
| Nelson et al. <sup>5</sup>        | 74          | 7/13       | 85.0%                 | 85% Anglo 15% Hisp           | unstated      |
| Kennedy et al. <sup>3</sup>       | 55.5        | 219/94     | 16.3%                 | 2.0% Aboriginal              | unstated      |

Anglo = Anglo-Saxon Hisp = Hispanic

## Overall

Self-management improves self-efficacy, despite the progressive, fluctuating nature of Parkinson's. It is limited by the health systems in which it is attempted, requiring a collaborative, flexible approach from Health Professionals. In the medical model, this becomes a source of frustration and conflict. Additionally, younger PlwP seem to have a higher desire to engage in self-management and collaborative medicine, requiring increased access and responsiveness from the services they are engaged with, a flexibility that is not possible in the current model of care<sup>7</sup>.

## Conclusion

Self-management is a valuable tool in the overall management for PlwP.. Self-management also requires that the health system be accessible, reactive and collaborative, rather than a medical model system focussed on acute issues, and that healthcare professionals acknowledge the PlwP as someone knowledgeable about their condition and able to play an expert role in their own care. Many healthcare professionals would require support and education around this manner of working. A Parkinson's Disease Nurse Specialist is well-placed to oversee and contribute a supervisory role for healthcare staff and PlwP as an element of a larger overall service for people living with the condition<sup>7</sup>

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