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**Wherry, Sally-Anne ORCID logoORCID: <https://orcid.org/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

Sally-Anne Wherry<sup>1</sup>, Chandni Das<sup>1</sup>, Christian Lueck<sup>1,2</sup>, Paul Dugdale<sup>1,2</sup>

<sup>1</sup> The Canberra Hospital and Health Services (CHHS)

<sup>2</sup> Australian National University Medical School

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.

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

## References

- World Health Organisation, 2013. Health Topic: Chronic Disease.
- Ghahari, S., Packer, T., 2012. Effectiveness of online and face-to-face fatigue self-management programmes for adults with neurological conditions. *Disability and Rehabilitation* 34, 564–573. doi:10.3109/09638288.2011.613518
- Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Richardson, G., Gardner, C., Gately, C., Rogers, A., 2007. The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *Journal of Epidemiology & Community Health* 61, 254–261. doi:10.1136/jech.2006.053538
- Lorig, K., Ritter, P.L., Plant, K., Laurent, D.D., Kelly, P., Rowe, S., 2013. The South Australia Health Chronic Disease Self-Management Internet Trial. *Health Education & Behavior* 40, 67–77. doi:10.1177/1090198112436969

## 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>

- Nelson, N., Wong, D., Lai, E., 2011. A self-management program for veterans and spouses living with Parkinson's disease: Self-management. *Journal of Nursing and Healthcare of Chronic Illness* 3, 496–503. doi:10.1111/j.1752-9824.2011.01125.x
- Tickle-Degnen, L., Ellis, T., Saint-Hilaire, M.H., Thomas, C.A., Wagenaar, R.C., 2010. Self-management rehabilitation and health-related quality of life in Parkinson's disease: A randomized controlled trial. *Movement Disorders* 25, 194–204. doi:10.1002/mds.22940
- Posma, E.R., van Weert, J.C., Jansen, J. & Bensing, J.M. (2009) Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*, 8 (1), p.1.
- Wherry, S.-A., 2015. A Systematic Review of Self-Management of Parkinson's Disease, as a Chronic Disease. Leeds Beckett UK.