

Covid Proof Self-Management Training for Caregivers of Patients with Parkinson's Disease

Recognition of the burden on the family is necessary for the continuity of care for the person with Parkinson's disease (PD),¹ especially during the Covid-19 pandemic with lockdown restrictions. Overburdening family members can lead to symptoms of anxiety and depression and ultimately to an inability to maintain the informal role as a caregiver. This, in turn, can lead to premature formal home care and admission to a nursing home. The economic benefits of informal care are considerable, and therefore, it is important to increase the resilience of informal caregivers in an early phase and prevent overload at a later stage of the care process. Recently, we have adapted the existing online intervention "Partner in Balance" (PiB), developed for informal caregivers of people with mild dementia,² to PD: Parkinson Partner in Balance (PPiB). PiB concerns a self-management training, aimed at maintaining a healthy balance in daily life (<http://www.partnerinbalance.org/>). It is given in a so-called "blended" form, in which four of nine online modules, tailored to the needs of the caregiver, are combined with face-to-face and online conversations with a coach. Module themes are acceptance, balance in activities, communication, coping with stress, focusing on the positive, insecurities and rumination, self-understanding, the changing family member, and social relations and support. PiB was experienced as feasible and appeared effective in terms of increased self-efficacy, perceived control, and quality of life compared to usual care.² The modular design of PiB and the online environment provided an excellent infrastructure to further develop PiB into the version for caregivers of patients with PD (PPiB).

In line with the Medical Research Council (MRC) framework, a stepwise approach was adopted to explore the potential user needs for PPiB, followed by a pilot evaluation to test its feasibility and the measurement tools before the effect evaluation. Fifteen participants, all women, were divided over three trained coaches, and 11 participants (73%) completed the program within 8 weeks. Reasons for dropout were overburdening

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TABLE 1. Outcome (measurement tools) after Parkinson partner in balance

Outcome	Pre-intervention mean (SD) n = 11	Post-intervention mean (SD) n = 9	P-value*
Self-efficacy	54.5 (12.6)	64.3 (11.3)	0.049
Perceived control	22.9 (5.7)	23.9 (5.9)	0.035
Anxiety	7.3 (4.8)	5.6 (3.5)	0.79
Depression	6.2 (3.8)	4.6 (3.0)	0.53

*Wilcoxon test; self-efficacy is based on the Caregiver Self-Efficacy Scale⁴ (higher scores indicate higher levels), perceived control is based on the Pearlin Mastery Scale⁵ (higher scores indicate higher levels), and anxiety and depression are both based on the Hospital Anxiety and Depression Scale⁶ (higher scores indicate higher levels with those >8 meaning clinically significant anxiety and depression).

at the start (n = 2) and insufficient motivation (n = 2). Data were collected at baseline and after 8 weeks, including self-report of self-efficacy, perceived control, and mood. Structured interviews with both the coaches and the (11) participants showed that PPiB met the need for support, offered sufficient information and tools, and was not experienced as burdensome. The support of a coach was experienced as positive and stimulating by all participants. Exploratory data analysis in 11 participants showed significant improvement for self-efficacy ($P = 0.049$) and perceived control ($P = 0.035$) but no significant change in mood (see Table 1).

In conclusion, PPiB is feasible and promising for caregivers of patients with PD and contributes to the development of self-management programs from a biopsychosocial perspective, which is still in its infancy in PD.³ The next step will be to determine its effectiveness. Parallel to this, the program has been implemented as an online intervention in healthcare, and its introduction has been very much appreciated during the Covid-19 pandemic in which e-health is the answer to continue healthcare and support. ■

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