

Care of Late Stage Parkinsonism (CLaSP-Study)

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Background Whilst the clinical problems, treatment and care needs of people with Parkinson's disease in the early stages are increasingly well known, there is little information on those in the late stages who have the greatest needs. This project aimed to assess the clinical problems and impact of late stage Parkinsonism on patients and their carers, examine what their medical and social needs are, as well as their use, costs and impact of health-care in six European countries.

Methods The CLaSP project included the following tasks: a full **systematic review** of the existing literature; **qualitative interviews** were conducted with people with late stage parkinsonism and with carers, **in-depth quantitative assessments** were performed in a large, representative multisite study including 692 individuals affected by late stage parkinsonism and their carers, and a pragmatic multicentre controlled **randomised trial** examining the impact of a single specialist review and written recommendations to the primary physician, reflecting current clinical practice, with six month follow-up.

Results We assessed 692 patients with Parkinson's disease and their carers. Amongst the motor and non-motor problems encountered by people with late stage parkinsonism and their carers, the features associated with the greatest impact on disability were falls/postural instability, bradykinesia, cognitive score and speech impairment. Carer burden was most affected by neuropsychiatric features of advanced Parkinson's disease. These motor and non-motor features were common in patients at home but particularly in those in nursing homes, who were often given other treatments for these problems in addition to the antiparkinsonian medications. The qualitative interviews revealed that in addition to facing the problems related to the disease itself and its treatment, the complex needs of this populations require a more flexible and personalised service than is currently received. It was also found that support for patients in their own homes helps those with Parkinson's keep independent and maintain a sense of themselves, and that provision of information helps them maintain some control and stay at home. Family caregivers were the main coordinators and monitors of care delivery, with significant impact on their own lives, demonstrated in the analysis of qualitative and quantitative data.

The treatment trial recruited 91 participants in the late stages of the disease. There was no significant difference in the main outcome measure (UPDRS ADL part), but despite treatment recommendations often not being followed (at least partially followed in only 64%) and underrecruitment there was greater improvement on the PDQ-8 in the intervention group (between-group difference = -3.7, p=0.02).

Taking the information from the literature reviews and the quantitative and qualitative studies, we devised a new tool to assess patients with late stage parkinsonism in any setting to provide the most appropriate care for patients in this complex late disease stage. Further data analysis is ongoing on longitudinal changes and health economic analysis.

Conclusion

As a result of this study, which highlighted the key problems and deficits in the existing care models, an assessment tool is being provided which will allow a structured and holistic assessment of patients in the advanced stages of Parkinsonism. In addition, recommendations for the holistic and personalised management of patients with advanced Parkinsonism are being made to address the unmet needs through care models in Europe. Our data, assessment tool and recommendations will provide the basis for better provision of treatment and care of this underserved population and support care for this severely affected patient group.