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Challenges and Opportunities in Late-stage Parkinson's Disease Care

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Introduction

Parkinson's disease progresses through several phases, beginning with the first diagnosis and progressing to the advanced stage, when motor difficulties arise and become problematic and finally to the late stage, which is the illness's last stage. LSPD has been designated a "orphan population" because to the scarcity of data on its care needs and the limited number of accessible therapy choices, owing to the scarcity or absence of clinical research focusing on these individuals. The treatment environment depicted above contrasts sharply with LSPD being the patient group with the most impairment and level of reliance, having more complicated care demands and having the largest health and economic effect among the various stages of Parkinson's disease [1].

Description

This narrative review tries to integrate data on the primary unmet care requirements and therapy problems in LSPD and proposes a solution in the form of a tailored care strategy. We will discuss clinical criteria, primary care demands and social burdens in LSPD and present example clinical care scenarios to create a proposal for new integrated palliative care [2].

The course of Parkinson's disease (PD) is defined by a non-linear deterioration of motor and non-motor symptoms (NMS), which may be modified by variables such as age at PD start, genetic background, predominant motor phenotype, presence of dysautonomia and REM sleep behaviour disorder. Patients ultimately reach the LS, which is clinically homogenous, independent of age at beginning, illness duration, or the existence of severe motor problems. Severe dependency in at least half of daily activities (ADLs) and postural instability despite dopaminergic treatment (Hoehn and Yahr are the diagnostic criteria for LSPD.

In LSPD, disability is no longer anchored to levodopa-induced motor complications, but rather to axial motor symptoms such as dysphagia, gait impairment, freezing of gait (FoG), postural instability and NMS such as hallucinations, cognitive decline, sleep/mood problems, urinary dysfunction, orthostatic hypotension (OH), constipation and pain. Most of these symptoms respond either partially or not at all to dopaminergic therapy. Taken as a whole, the clinical phenotype of LSPD dominated by falls, dysphagia, bilateral more symmetrical Parkinsonian symptoms and cognitive impairment may suggest the one of atypical Parkinsonism thought after a prolonged disease course. Among all NMS, cognitive decline and dementia are major factors to functional decline and loss of independence in ADLs [3].

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A solid practise point for symptomatic treatment is to use L-dopa, preferably as monotherapy and at the lowest feasible dose. Other (additional) dopaminergic therapies, such as dopamine agonists, catechol-O-methyl transferase inhibitors and monoamine oxidase-B inhibitors, are more likely to cause hallucinations, confusion, or OH in elderly and frail PD patients and, as a result, should be used with caution at this stage of the disease. L-dopa has been demonstrated to be beneficial for stiffness and tremor, particularly in non-demented individuals with tremor dominance or dyskinesia in LSPD. For appendicular Parkinsonian symptoms, these individuals may benefit from careful L-dopa dosage increases [4].

On the other hand, the effect of L-dopa on axial characteristics such as speech impairment, postural instability and FoG is frequently minimal or nonexistent. As a result, a disproportionate increase in L-dopa dose to target these traits may be ineffective and cause major side effects, such as increased disorientation or OH. The treatment of NMS is based on the clinical data available for earlier stages of Parkinson's disease. Nonetheless, the dosage therapeutic response, tolerance and adverse event profile in LSPD may be unique, limiting its application. Notably, regular assessment by a movement disorder expert with specific treatment suggestions has been demonstrated to improve the quality of life of LPSD patients when compared to follow-up alone by other physicians such as a general practitioner.

Non-pharmacological techniques are an essential part of LSPD management. Non-pharmacological therapies include physiotherapy to reduce the risk of falls and joint deformities, speech and language therapy to avoid aspiration pneumonia and cognitive training. When evaluating the complicated care demands of Parkinson's disease patients, a multispecialty strategy has been proposed as the most appropriate method for personalised and comprehensive care delivery to meet care complexity in PD throughout the disease course. However, the viability of these techniques in LSPD has yet to be properly investigated, which must take into account the existence of cognitive impairment and mobility limitations that lead to an intervention being administered at home rather than in the clinic.

Patients with LSPD who have previously received device-aided therapies (DAT), such as deep brain stimulation (DBS), levodopa-carbidopa intestinal gel (LCIG), or continuous apomorphine subcutaneous infusion (CSAI), represent a small subset of LSPD patients but are expected to require a more specialised level of care. CSAI is a disadvantage of DATs. There have been no reports of LSPD patients receiving continued CSAI therapy, as AEs such as hallucinations, disorientation and OH likely cause its withdrawal before a patient reaches LSPD [5].

Previous research has demonstrated that the adoption of community-based specialised palliative care across numerous life-threatening diseases reduces hospital care expenditures. The PD Pal model is also testing the adoption of home monitoring via telemedicine and wearable technologies for the evaluation of motor symptoms and as a facilitator of the PD Pal intervention. Telemedicine may be more useful for LSPD patients living at home by potentially postponing severe disease consequences and providing more continuous care delivery. Furthermore, the PD Pal project created the "Best Care for People with Late-Stage Parkinson's Disease" curriculum toolbox, which was deployed as a Massive Online Open Course for ACP training.

Conclusion

Because of the expected exponential increase in PD prevalence in

the general population, the prevalence of LSPD patients will rise, forcing physicians, other health care professionals and health care systems to deal with a PD population in need of specialised and complex care, ideally delivered in a coordinated framework. We discussed the clinical diagnosis of LSPD in this review, highlighting its most unpleasant motor and NMS symptoms and provided information on how such symptoms might negatively affect carers. We discussed how frailty affects these individuals once they are admitted to hospitals or nursing homes.

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Conflict of Interest

No potential conflict of interest was reported by the authors.

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