

## Presidents Round

### Scientific Presentation: PD (Parkinson's Disease)

#### 39 THE EXPERIENCES OF TREATMENT BURDEN AMONG PEOPLE WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS: A SYSTEMATIC REVIEW

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**Introduction:** Treatment burden is the “workload of healthcare and its impact on patient functioning and well-being”. High treatment burden may lead to non-adherence to treatment regimens, poor health outcomes, poor quality of life and wasted healthcare resources. Treatment burden among people with Parkinson's (PwP) and their caregivers has not been previously explored.

**Methods:** Using five electronic databases (MEDLINE, Embase, CINAHL, Scopus and PsychInfo), we conducted a systematic review of studies published since 2006 when the first National Institute for Clinical Excellence (NICE) Clinical Guideline for Parkinson's Disease was published. This allows an understanding of the impact of current healthcare systems on treatment burden. We included qualitative and mixed-method studies with a qualitative component that reported data from PwP and/or caregivers. Quantitative studies, qualitative data from clinical trials not related to usual care and grey literature were excluded. Two reviewers independently screened articles and extracted data. Data analysis was conducted using framework analysis.

**Results:** 1757 articles were screened, and 39 included in this review. Understanding treatment burden among PwP and their caregivers was not the primary aim in any of the included studies. They described the experiences of those living at home and during hospital or care home admissions. Issues with medications (adherence to advice, effectiveness, side-effects and timing), obtaining appropriate levels of information and healthcare provision (lack of integrated care, care coordination and person-centred approach) were among factors that exacerbate treatment burden experienced by PwP and caregivers. Both reported the impact of Parkinson's on their daily lives, physical and mental exhaustion of self-care and limitations on their role and social activities.

**Conclusion:** This review describes considerable treatment burden experienced by PwP and their caregivers and its major influences including aspects of current healthcare provision. Future research should focus on patient-centred care with service redesign to improve this treatment burden.