

The experiences of treatment burden in people with Parkinson's and their caregivers: a systematic review of qualitative studies

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Objective

- To explore the experiences of treatment burden among people with Parkinson's (PwP) and their caregivers.

Background

- Treatment burden** is defined as *'the workload of healthcare and its impact on patient well-being and functioning'*.
- High treatment burden is associated with poor adherence, wasted resources, poor quality of life and poor health outcomes.
- Clinical experience suggests PwP and their caregivers may experience high treatment burden. Identifying the factors that impact treatment burden in Parkinson's can offer insight into strategies to mitigate them.

Methods

- Using five electronic databases, a systematic review of studies published from year 2006 was conducted. Qualitative and mixed-methods studies with a qualitative component that reported data from PwP and/or caregivers related to usual care in Parkinson's were included. Quantitative studies and non-English articles were excluded. Data synthesis was conducted using framework synthesis.

Results

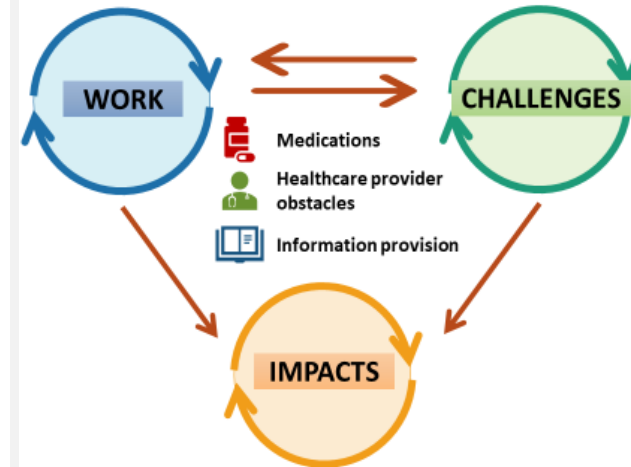
1757 articles were screened, and 39 articles included. Understanding treatment burden was not the primary aim in any of the included studies.

The **main issues of treatment burden** in Parkinson's were:

- Work of taking multiple **medications** including frequent adjustment of medication timings and doses, precise medication timings with fixed schedules and challenges with medication adherence and side-effects.
- Healthcare provider obstacles** including lack of patient-centred care and care coordination, poor patient-provider relationships, inflexible organizational structures, lack of access to services and issues in care home or hospital setting.
- Learning about Parkinson's and challenges with **information provision**.

The treatment burden led to **physical and mental exhaustion of self-care** and **limitations on the role and social activities** of PwP and caregivers.

Main issues of treatment burden in Parkinson's



Conclusions

- This review identified the experiences and factors influencing treatment burden in Parkinson's.
- Potential strategies to improve the treatment burden in Parkinson's could be implementing patient-centred approach to care (individual level) and improving access and care coordination between services (system level).
- Future research is needed to fully understand and determine the modifiable factors of treatment burden in Parkinson's.