

## PATIENT AND SPOUSE PERCEPTIONS OF COGNITIVE AND NEUROPSYCHIATRIC SYMPTOMS IN PARKINSON'S DISEASE: IMPLICATIONS FOR DISTRESS, QUALITY OF LIFE AND RELATIONSHIP SATISFACTION

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**Introduction:** People with Parkinson's Disease (PD) experience a range of Cognitive and Neuropsychiatric Symptoms (CNPS), including depression, fatigue, anxiety, hallucinations and dementia. Patients rate CNPS as among the most important and challenging features of their illness (Politis et al., 2010), yet CNPS is less well understood than motor symptoms. Many loved ones of individuals with PD become informal caregivers. This study investigated the impact of CNPS on carers' and patients' wellbeing as individuals and on couples' relationship satisfaction.

**Method:** This cross-sectional study involved 31 couples living with PD. Clinically valid screening tools and a semi-structured interview assessed the intensity of CNPS and CNPS-related distress. Self-report measures assessed mood, overall distress, health-related quality of life (HRQoL), and relationship satisfaction.

**Results:** Within couples, patients and carers agreed on the levels of total CNPS intensity across the 14 CNPS assessed. Patients and carers within couples disagreed with their views of the presence of specific symptoms, particularly hallucinations, disinhibition, irritability, agitation and aggression, apathy and delusions. Discordance was not associated with distress or relationship satisfaction.

Patient overall distress was positively predicted by couples' ratings of patient CNPS-related distress. Carer overall distress was positively predicted by carers' CNPS-related distress, caregiving-related distress and HRQoL. Carer relationship satisfaction was best predicted by caregiving-related distress. No predictors of patient relationship satisfaction were identified.

**Discussion:** This study demonstrates that relying only on patient or carer reports is clinically invalid. Patients' and carers' distress, experiences of PD-related CNPS, and any discordance within couples must be proactively and accurately assessed and used to inform interventions.

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## AVOIDABLE EMERGENCY VISITS BY HOME HOSPICE PATIENTS: IS THERE A SOLUTION?

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**A**lthough research has shown the majority of terminally ill people would prefer to die at home, many who are utilizing home-based hospice end up in the emergency room during their final weeks of life. This integrative review evaluates published studies identifying the causative factors and impact of emergency room visits among home-based hospice patients and their family/caregivers in the last few weeks of life from January 2005 to current. A search of the electronic databases EBSCO Host was utilized as well as the U.S National Library of Medicine/Pub Med, Google Scholar, and the Cumulative Index of National and Allied Health Literature (CINAHL) using key words: Nurse Practitioner, palliative care, hospice, end of life care, and emergency. Data was evaluated using a constant comparative approach as well as thematic content analysis to identify key issues. Seventeen studies from the United States were included as well as ten studies from other countries. From these studies, several factors are addressed including: primary reasons for accessing emergency services, the impact on perceived quality of life and caregiver bereavement outcomes, and prevention and guidance aimed towards reducing hospital admissions. The impact of potentially avoidable end-of-life hospital visits by the terminally ill has been shown to adversely affect quality of life and bereavement outcomes. A comprehensive and coordinated specialist palliative care approach may help minimize the number of patients presenting to the emergency department unnecessarily, thereby helping to maintain them in the setting of their choice for the provision of end-of-life care.