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MDS Abstract

Identification of barriers preventing disclosure of Non-Motor Symptoms in Parkinson's patients to Healthcare Providers

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Objective

1) To identify patient barriers to help-seeking for non-motor symptoms (NMS) from their Parkinson's healthcare provider,
2) To determine whether barriers are symptom specific (e.g. embarrassment disclosing sexual problems) or patient specific (e.g. misattribution of a range of NMS to old age).

Background

NMS are common in Parkinson's disease (PD) and cause significant distress and decreased quality of life. A high rate of non-declaration of NMS by patients to healthcare providers means that many NMS remain unrecognized and untreated, even in specialist clinical services. Current understanding of the factors preventing disclosure of NMS to healthcare professions is limited.

Method

358 PD patients completed the Non-motor Symptom Questionnaire and a barriers to help-seeking for NMS questionnaire developed from previous qualitative work. A Generalised Estimating Equation was used to determine whether barriers were symptom or individual specific.

Results

The sample had a mean age of 66.3 years, mean disease duration of 5.9 years and were 52.5% male. Urinary urgency was the most common NMS (65%) and sexual dysfunction was the symptom most frequently not disclosed (52%). Barriers to symptom disclosure varied dependent on symptom type. Pain and sleep problems were commonly not thought to be symptoms of PD. Bowel and bladder symptoms were often simply accepted as part of daily life and participants were unsure about the availability of effective treatments. Patients experienced embarrassment discussing sexual dysfunction.

Conclusion

Our results highlight the barriers which prevent PD patients reporting NMS to their Parkinson's clinical team and the diversity of these barriers between different NMS. Strategies to improve rates of reporting must target individual NMS. For example, effective interventions might provide information regarding treatment efficacy for bowel and bladder symptoms or develop communication skills and normalising information for sexual dysfunction. The study provides the information needed to develop such individualised interventions. Increasing rates of disclosure of NMS by patients to their Parkinson's healthcare providers will ensure patients receive appropriate clinical care which may increase quality of life and well-being.