D.1 Information needs of people with Parkinson's disease and their families and carers

D.1.1 Impulse control behaviours

Bibliographic reference	Phu,A.L., Xu,Z., Brakoulias,V., Mahant,N., Fung,V.S., Moore,G.D., Martin,A., Starcevic,V., Krause,M., 20140821, Effect of impulse control disorders on disability and quality of life in Parkinson's disease patients, Journal of Clinical Neuroscience, 21, 63-66, 2014
Full citation	Phu,A.L., Xu,Z., Brakoulias,V., Mahant,N., Fung,V.S., Moore,G.D., Martin,A., Starcevic,V., Krause,M., 20140821, Effect of impulse control disorders on disability and quality of life in Parkinson's disease patients, Journal of Clinical Neuroscience, 21, 63-66, 2014
Country/ies where the study was carried out	Australia
Study type	Cohort study
Aim of the study	To examine the effect of impulse control disorder on quality of life in Parkinson's disease patients.
Study dates	Study carried out between Jan 2009 and March 2011. received Oct 2012 accepted Feb 2013 published 2014
Source of funding	Parkinson's Australia and the Nepean Research fund
Sample size	N = 100
Inclusion criteria	Idiopathic PD according to Queen square brain bank criteria
Exclusion criteria	Those with active psychotic symptoms or severe cognitive impairment or other reasons which preclude an interview i.e. language barriers
Details	All patients interviewed by an experienced psychiatrist using expanded structured clinical interview from DSM-IV for obsessive compulsive disorder related spectrum disorders (OCSD) Corresponding diagnoses based on DSM IV criteria and on research criteria where DSM does not provide diagnostic criteria Mini international neuropsychiatric interview used to assess presence and severity of suicidality PD symptoms assessed by UPDRS III and UPDRS ADL MMSE and MOCA used for cognitive testing LEDD calculated for levodopa and DA's QoL measured using PDQ39
Interventions	N/A
Results	N ICD = 15, N no ICD = 85

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	mean age ICD = 64.6 (7.7), no = 67.6 (9.2) ICD male = 80%, no = 67% PD duration ICD = 0.0 (5.4), no = 7.2 (6.3) ICD and PDQ39 scores ICD mean total PDQ39 = 59 (SD = 29) (95%CI: 45 to 73) , no ICD = 41 (SD=27) (95%CI: 36 to 47) - MD = 18 (2.24 to 33.76) ADL ADL significantly reduced in patients suffering from ICRD compared to those without ICRD - regression coefficient = 3.0 (1.4) p=0.04 Major depressive disorder and ICD Incidence of MDD in ICD was 4/15 (27%) in ICD patients compared to 9/85 (11%) of patients without an ICD. (Odds ratio calculated using RevMan: OR =3.07, 95%CI: 0.86 to 11.69)
Overall Risk of Bias	NICE cohort study checklist: 1. Method of allocation to treatment groups was unrelated to potential confounding factors: N/A - no treatment 2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders? NA; patients allocated on basis of ICD or not, no intentional allocation 3. Groups were comparable at baseline, including all major confounding and prognostic factors? yes, baseline characteristics similar 4. Based on above, was selection bias present? If so, direction of effect? No selection bias present 5. Comparison groups received same care apart from interventions studied? Yes, all assessment procedures the same for all participants 6. Participants receiving care were kept blind to treatment allocation? NA 7. Individuals administering care were kept blind to treatment allocation? NA 8. Based on above, was performance bias present? If so, direction of effect? NO - not applicable 9. All groups followed for equal length of time? No longitudinal follow up 10. How many pts did not complete follow-up? No longitudinal follow up11. Groups were comparable for treatment completion? No treatment 12. Groups were comparable with respect to availability of outcome data? Yes 13. Based on above, was attrition bias present? If so, direction of effect? No 14. Study had appropriate length of follow up? No longitudinal follow up 15. Study used precise definition of outcome? Yes. Well-validated measures used. 16. Valid and reliable method was used to determine outcome? Yes. Well-validated measures used 17. Investigators kept blind to participant's exposure to intervention? No intervention 18. Investigators kept blind to other important confounding factors? NA 19. Based on above, detection bias present? If so, direction of effect? NO No serious bias present

Bibliographic reference	**Phu,A.L., Xu,Z., Brakoulias,V., Mahant,N., Fung,V.S., Moore,G.D., Martin,A., Starcevic,V., Krause,M., 20140821, Effect of impulse control disorders on disability and quality of life in Parkinson's disease patients, Journal of Clinical Neuroscience, 21, 63-66, 2014**
Other information	None

Bibliographic reference	**Mestre,T.A., Teodoro,T., Reginold,W., Graf,J., Kasten,M., Sale,J., Zurowski,M., Miyasaki,J., Ferreira,J.J., Marras,C., Reluctance to start medication for Parkinson's disease: A mutual misunderstanding by patients and physicians, Parkinsonism and Related Disorders.20 (6) (pp 608-612), 2014.Date of Publication: June 2014., 608-612, 2014**
Full citation	Mestre,T.A., Teodoro,T., Reginold,W., Graf,J., Kasten,M., Sale,J., Zurowski,M., Miyasaki,J., Ferreira,J.J., Marras,C., Reluctance to start medication for Parkinson's disease: A mutual misunderstanding by patients and physicians, Parkinsonism and Related Disorders.20 (6) (pp 608-612), 2014.Date of Publication: June 2014., 608-612, 2014
Country/ies where the study was carried out	Portugal, Canada, and Germany
Study type	Cross-sectional observational study
Aim of the study	To study reluctance to start medication for PD motor symptoms, namely its prevalence, underlying reasons, drug-specificity, and associated delay in the start of PD medication
Study dates	Not reported
Source of funding	Not reported
Sample size	469 participants (201 PD patients, 268 physicians)
Inclusion criteria	Clinical diagnosis of PD by a movement disorders specialist Recommendation to start anti-PD drugs in the preceding 5 years
Exclusion criteria	Patients with cognitive impairment reported in clinical records
Details	Patients were interviewed with a structured questionnaire conducted by a study investigator other than the caring physician. The questionnaire included questions using a five-point Likert scale to estimate the degree of reluctance to start medication for PD and individual anti-PD drug classes. Reasons for the delay of starting anti-PD drugs were also asked. Open questions were included to determine the causes for reluctance to start medication. Demographic and PD-related information were abstracted from medical records. Physicians were sent an electronic survey that included various multiple-choice questions covering the same topics included in the patient questionnaire. A list of reasons for reluctance to start medication was provided and physicians were asked to order the reasons listed from the most to the least common, in the patient's point of view.
Interventions	N/A

Bibliographic reference	**Mestre,T.A., Teodoro,T., Reginold,W., Graf,J., Kasten,M., Sale,J., Zurowski,M., Miyasaki,J., Ferreira,J.J., Marras,C., Reluctance to start medication for Parkinson's disease: A mutual misunderstanding by patients and physicians, Parkinsonism and Related Disorders.20 (6) (pp 608-612), 2014.Date of Publication: June 2014., 608-612, 2014**
Results	Causes for reluctance to start medication: Patients - 62 participants expressed their reasons for reluctance out of the 82 who reported some degree of reluctance. The most common reason for reluctance to start medication was the fear of side effects (n=35; 55.6%), followed by non-acceptance of diagnosis (n=23, 36.5%). Other frequently reported reasons were a general dislike for medications (n=17, 27%) and scepticism regarding the efficacy of medication (n=10, 15.9%). Treatment-induced dyskinesia (n=5), sleep problems (n=4) and impulse control disorders (n=3) were the most commonly reported specific adverse effects of concern. Physicians - The patient's fear that antiparkinsonian medication would have a temporally limited benefit (n=92/267, 34.5%) was judged to be the most common cause for reluctance to start medication (p=0.0065). A dislike of chronic medication (n=67/236, 28.4%) was judged to be the second most common reason (p<0.0001). Non-acceptance of the diagnosis (n=24/236, 10.1%) was rarely selected for higher levels of reluctance.
Overall Risk of Bias	1. Method of allocation to treatment groups was unrelated to potential confounding factors: N/A - no treatment 2. Attempts were made within the design or analysis to balance the comparison groups for potential confounders? NA - no intentional allocation 3. Groups were comparable at baseline, including all major confounding and prognostic factors? No, participants were only comparable in terms of age and sex. 4. Based on above, was selection bias present? If so, direction of effect? Unclear. 5. Comparison groups received same care apart from interventions studied? Unsure. 6. Participants receiving care were kept blind to treatment allocation? NA 7. Individuals administering care were kept blind to treatment allocation? NA 8. Based on above, was performance bias present? If so, direction of effect? NA 9. All groups followed for equal length of time? No longitudinal follow up 10. How many pts did not complete follow-up? No longitudinal follow up 11. Groups were comparable for treatment completion? No treatment 12. Groups were comparable with respect to availability of outcome data? Yes 13. Based on above, was attrition bias present? If so, direction of effect? NA 14. Study had appropriate length of follow up? No longitudinal follow up 15. Study used precise definition of outcome? Yes. 16. Valid and reliable method was used to determine outcome? Unclear.17. Investigators kept blind to participant’s exposure to intervention? No intervention 18. Investigators kept blind to other important confounding factors? NA 19. Based on above, detection bias present? If so, direction of effect? Unclear Likely high risk of bias.
Other information	None