



## Barriers to reporting non-motor symptoms to health-care providers in people with Parkinson's



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### ABSTRACT

**Background:** Non-motor symptoms (NMS) are common in Parkinson's disease (PD) and cause significant distress. A high rate of non-declaration of NMS by patients to healthcare providers (HCP) means that many NMS remain untreated. Current understanding of the factors preventing disclosure of NMS to HCPs is limited. The present study aimed to i) further assess the prevalence of NMS and associated distress, ii) establish current rates of NMS reporting across a range of sources, and iii) explore overall and any symptom specific barriers to help-seeking for NMS.

**Methods:** 358 PD patients completed a cross-sectional survey of NMS severity, reporting and barriers to help-seeking. A series of Generalised Estimating Equations were used to determine whether barriers were symptom specific.

**Results:** A mean of 10.5 NMS were reported by each patient. Rates of non-reporting of NMS ranged from 15 to 72% of those experiencing distressing symptoms. The most commonly reported barriers to help-seeking were acceptance of symptoms; lack of awareness that a symptom was associated with PD, and belief that no effective treatments were available. Symptom specific barriers were found for sexual dysfunction (embarrassment), unexplained pain and urinary problems (belief about lack of treatment availability).

**Conclusion:** A diverse range of barriers prevent PD patients reporting NMS to HCPs and these barriers differ between NMS. The study provides the foundations for developing interventions to increase reporting by targeting individual NMS. Increasing rates of help-seeking for NMS by patients to their Parkinson's healthcare providers will increase appropriate clinical care which may improve quality of life and well-being.

### 1. Introduction

Non-motor symptoms (NMS) of Parkinson's disease (PD) are common and problematic. Up to 98% of people with Parkinson's report experiencing at least one NMS [1–3]. Several studies have demonstrated the negative impact of NMS on patient quality of life (QoL) and psychological well-being which is often found to be greater than the impact attributable to motor symptoms [4–8]. Mood symptoms, urinary symptoms, fatigue and leg pain are amongst the most commonly reported NMS [1–3]. Other common symptoms include unexplained pain, bowel problems, sleep problems and issues with memory and concentration.

The issue of non-reporting of NMS by patients to clinicians has been highlighted by Chaudhuri et al. [9,10]. In a large scale European survey they found that in some cases over 50% of patients experiencing NMS did not report them to a healthcare provider (HCP). Despite several reviews outlining potentially efficacious treatments for a range of NMS [11–16], they are still not routinely screened for, even in specialist centres [9]. This failure to screen for NMS combined with a lack of reporting by patients results in distressing symptoms remaining untreated.

Preliminary research based on a single question 'why have you not told your healthcare provider' in response to self-reported NMS [10] highlighted a range of potential barriers. These barriers included lack of

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awareness that symptoms were related to PD, embarrassment at discussing symptoms, and limited time in consultations for discussing non-motor issues. More recently a theoretically driven qualitative study explored the complexity of barriers to help-seeking for NMS in more depth [17]. A total of 23 individual barriers to help-seeking for a range of NMS were identified. Uncertainty about the link between NMS and PD, and lack of clarity around the availability of treatments were common barriers to reporting a range of NMS. However some barriers appeared to be symptom specific. For example embarrassment and communication difficulties were common for potentially sensitive symptoms such as sexual dysfunction, bowel and bladder problems.

Several questions remain to be answered if we are to improve our understanding of the factors which prevent patients reporting NMS to their HCP and consequently, how we might overcome these challenges. The complex range of barriers to help-seeking identified by Hurt et al. [17] need to be validated in a larger sample of people experiencing undeclared NMS to ascertain their generalisability to all people with Parkinson's. It remains unclear whether barriers to symptom reporting are patient related or if barriers are symptom specific.

The aims of the present study were three fold: i) to further assess the prevalence of NMS and associated levels of distress, ii) to establish current rates of NMS reporting across a range of formal and informal sources, and iii) to explore overall and any symptom specific barriers to help-seeking for NMS.

## 2. Methods

### 2.1. Design

Data on presence of non-motor symptoms, help-seeking behaviour and barriers to help-seeking was collected in a large-scale cross-sectional survey. Data were collected using an online survey tool (Survey Monkey) [18], and using paper-based questionnaires. Data collection took place between March 2015 and August 2015. Ethical approval was granted by Cornwall and Plymouth Research Ethics Committee (ref:14/SW/0099).

### 2.2. Measures

The NMSQuest [1] which consists of 30 common NMS, was used to assess the presence of NMS. For the purpose of the present study the item 'altered interest in sex' was replaced by two items, 'increased' and 'decreased' interest giving a total of 31 items. For each symptom reported as present over the past 12 months, the participant was asked to rate how distressing the symptom was from 0 (not at all) to 3 (severely distressing). They were also asked if they had sought help for the symptom and, if so, from whom using a pre-defined list of sources of help whom patients with Parkinson's have regular contact (Formal sources: Consultant (senior doctor), Parkinson's Nurse Specialist and General Practitioner; Informal sources: Pharmacist, friends and family). Within the UK National Health Service patients with Parkinson's may receive management of their PD from a range of sources most commonly a Consultant Neurologist (a senior doctor specialising in movement disorders) or a Consultant Geriatrician (a senior doctor specialising in care of older adults). Many patients not requiring complex management are treated by their General Practitioner in primary care. All patients should have access to a Parkinson's Disease Specialist Nurse (a nurse trained and specialising in the management of PD). Those experiencing distressing symptoms who had not sought help from an HCP were asked to endorse any and all relevant barriers from a pre-defined list based on the findings of Hurt et al. [17] (The full list of barriers is available in the supplementary materials, Table S1). A self-report measure of impairment of activities of daily living associated with PD, the Parkinson's Activities of Daily Living Scale (PADL) [19] was used as a proxy for disease severity. Clinical and demographic data were collected for all participants (see Table 1).

**Table 1**  
Sample characteristics (N = 358).

Characteristic	Mean/N	Range/Percentage
Age	66.3 years	51–83 years
Gender		
Male	186	52.5%
Female	168	47.5%
PD duration	5.9 years	1–33 years
PADL	2.3	1–5
Employment status		
Full-time	45	12.6%
Part-time	25	7%
Unemployed	10	2.8%
Retired	228	63.9%
Retired due to health	49	13.7%
Education		
Left school before 15	42	11.9%
GCSE or equivalent level	76	21.5%
A-levels or equivalent	56	15.8%
University level	180	50.9%
Ethnicity		
White	323	90.7%
Asian/Asian British	17	4.8%
Black/African/Caribbean/Black British	10	2.8%
Other	6	1.7%
Marital status		
Married/civil partnership/cohabiting	277	77.4%
Widowed	29	8.1%
Single (never married)	28	7.8%
Divorced/separated	19	5.3%
Other	5	1.4%
Primary PD HCP		
GP	24	6.8%
Consultant Neurologist	253	72.1%
Consultant Geriatrician	14	4.0%
PD Nurse	57	16.2%
Other	3	0.9%

### 2.3. Participants

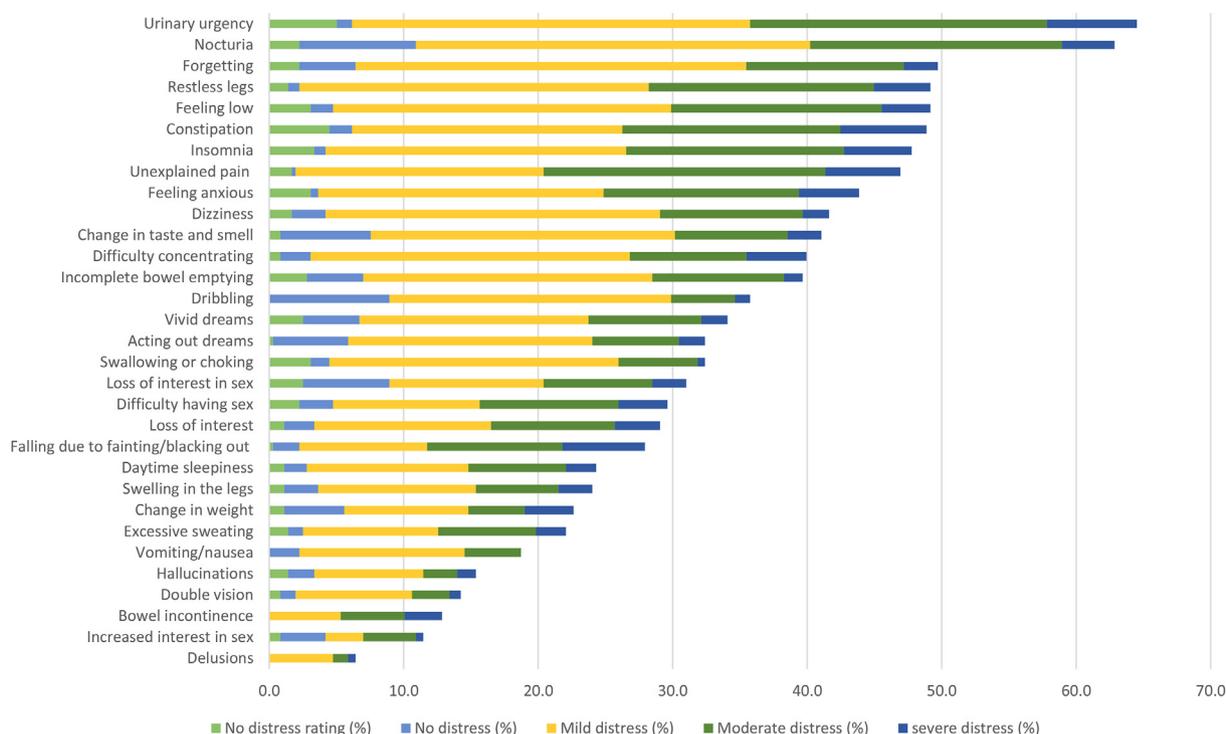
Participants were recruited via the Parkinson's UK Research Support Network and neurology outpatient clinics across south London, UK. All participants had the option of completing an online or paper questionnaire. To provide a broad and inclusive sample no eligibility criteria were set beyond a clinical diagnosis of Parkinson's disease, ability to give informed consent and complete the study questionnaires.

### 2.4. Sample size and statistical analysis

Categorical data on presence/absence of each barrier were collected from each patient for all reported symptoms. Data were modelled to compare the distribution of barriers across different NMS. Logistic Generalised Estimating Equation (GEE) Models were run for each barrier separately, with the binary indicator variable for presence of barrier as the outcome, and the 31 indicator variables for symptoms as explanatory variables. This model allowed us to assess the difference in the probability of choosing the barrier by comparing symptom 2 to symptom 1, and symptom 3 to symptom 1, etc. As a general rule, an average sample size of at least 300 is required for a maximum of 30 parameters (symptoms). For each model we selected symptoms where at least 1 person reported the barrier as a reason for not reporting a symptom.

## 3. Results

A total of 358 participants were recruited (206 via Parkinson's UK, 150 from NHS trusts and 2 from other sources). 159 paper questionnaires were completed and the remaining 199 questionnaires were completed online. The sample characteristics are shown in Table 1.



**Fig. 1.** Frequency of NMS and associated level of distress across total sample (N = 358) Symptoms are ranked by prevalence from high to low. No distress rating = symptom was endorsed but distress data missing.

### 3.1. Frequency of non-motor symptoms

The frequency of NMS reported by the sample and the associated levels of distress are shown in Fig. 1, with symptoms ranked from most to least frequent. In line with previous research, urinary symptoms were the most commonly experienced NMS and delusions the least common. Bowel incontinence, unexplained pain and falling due to fainting/blacking out were identified as the most likely to be associated with significant distress when present, while swallowing/choking, nausea/vomiting and dribbling were rated least likely to cause distress. Overall the proportion of participants rating their NMS as moderately or severely distressing ranged from 16.4% to 58.9%.

The mean number of NMS experienced by each patient over the previous 12 months was 10.5 (SD = 5.4, range = 0–25). NMS burden was calculated using the cut-offs provided by Chaudhuri et al. [20]. Only four of the 358 participants had no NMS (1.1%), 18.4% reported 1–5 NMS (mild burden), 27.7% reported 6–9 symptoms (moderate burden), 26% reported 10–13 symptoms (severe burden) and 26.8% reported greater than 13 NMS representing very severe burden.

### 3.2. Help-seeking for NMS

The frequency of declaration of NMS to a range of formal and informal sources is shown in Table 2. For 22 of the 31 symptoms at least 30% of participants who described experiencing distressing NMS had not reported them to an HCP. ‘Loss of interest in sex’ was the least reported NMS with only 28% of patients telling their HCP, although the figure rose to 48% when informal sources of help were included. Falling due to fainting or blacking out had the highest reporting rate to an HCP with 85% of patients experiencing the symptom reporting it, rising to 92% when informal sources of help were included. A large proportion of patients reported their NMS to a family member or friend, even when not reporting them to an HCP. For 25 of the 31 NMS the PD nurse was the HCP that symptoms were most commonly reported to.

### 3.3. Barriers to reporting NMS

Barriers to help-seeking were recorded for those with distressing NMS who had not reported their symptoms to an HCP. Eighteen barriers to help-seeking were endorsed by one or more participants (range 10–292), with 8 barriers endorsed by 100 participants or more. These included ‘Acceptance of the symptom as part of life’ (n = 292), ‘Uncertainty that effective treatment is available’ (n = 222), ‘Uncertainty whether the symptom is part of PD’ (n = 206), ‘Belief that the symptom is not serious’ (n = 156), ‘Concern that treatment will require change of PD medication or taking extra medication’ (n = 125), ‘Not a priority at the time’ (n = 114), ‘Belief that raising the problem not socially acceptable’ (n = 108), and ‘Lack of priority to NMS in the consultation’ (n = 108). A series of chi-squared tests were run to compare barrier reporting between males and females. No significant differences found at p < 0.05.

A full break down of barrier frequency is given in the supplementary information (Table S2).

As no barriers to reporting delusions were endorsed this symptom was excluded from further analyses. Additionally, due to the small number of participants reporting the barrier ‘speaking to an HCP of the same gender’ (N = 10) this barrier was excluded from further analyses.

A series of GEEs were used to determine whether certain barriers to help-seeking were associated with specific symptoms. Inferential statistics for the barriers found to have statistically significant associations with specific NMS are presented in Table 3. The full inferential statistics for all models are available from the authors on request.

Symptoms relating to sexual function were associated with embarrassment and being difficult to talk about. Urinary urgency and unexplained pain were associated with acceptance, were not associated with PD and not perceived as treatable.

## 4. Discussion

The NMS frequencies found in the present study are in line with

**Table 2**  
Declaration of NMS by source of help.

NMS	Not reported at anyone %	Consultant %	PD Nurse %	GP %	Pharmacist %	Friend or family %	Not reported to HCP* %
Urinary urgency	20.3	31.6	<b>54.5</b>	37.7	6.1	42	29.0
Nocturia	21.8	32	<b>53.3</b>	35.1	4.9	41.3	29.8
Forgetting	18.0	35.4	<b>48.9</b>	26.4	6.7	53.9	37.1
Restless legs	21.6	34.1	<b>54</b>	24.4	4.5	50	32.4
Feeling low	25.6	31.3	<b>44.9</b>	30.1	7.4	52.8	40.9
Constipation	14.9	34.9	<b>55.4</b>	42.3	6.9	34.3	22.3
Insomnia	12.3	45	<b>60.2</b>	35.1	6.4	54.4	22.2
Unexplained pain	16.7	39.3	<b>48.8</b>	43.5	7.1	48.2	29.8
Feeling anxious	24.2	31.2	<b>53.5</b>	28.7	7	48.4	35.0
Dizziness	24.2	32.2	<b>47</b>	33.6	7.4	49	34.9
Change in taste and smell	25.9	36.1	<b>44.9</b>	21.8	4.1	42.9	39.5
Difficulty concentrating	23.8	31.5	<b>47.6</b>	27.3	7	46.9	42.0
Incomplete bowel emptying	44.4	19.7	<b>40.1</b>	27.5	7	23.9	48.6
Dribbling	32.8	28.9	<b>46.9</b>	20.3	3.1	31.1	39.1
Vivid dreams	15.6	41.8	<b>57.4</b>	24.6	4.9	62.3	31.1
Acting out dreams	14.7	32.8	<b>54.3</b>	24.1	6	62.9	32.8
Swallowing or choking	21.6	31	<b>56.9</b>	21.6	6	46.6	37.1
Loss of interest in sex	52.3	11.7	13.5	<b>16.2</b>	1.8	31.5	72.1
Difficulty having sex	44.3	15.1	15.1	<b>31.1</b>	2.8	34	58.5
Loss of interest	33.7	24	<b>45.2</b>	20.2	4.8	42.3	47.1
Falling due to fainting/blacking out	8.0	53	<b>65</b>	53	10	64	15.0
Daytime sleepiness	12.6	37.9	<b>57.5</b>	25.3	11.5	57.5	24.1
Swelling in the legs	16.3	29.1	41.9	<b>53.5</b>	2.3	50	25.6
Change in weight	22.2	35.8	40.7	<b>44.4</b>	4.9	46.9	29.6
Excessive sweating	27.8	35.4	<b>41.8</b>	34.2	5.1	44.3	43.0
Vomiting/Nausea	25.4	32.8	<b>38.8</b>	29.9	6	43.3	41.8
Hallucinations	16.4	49.1	<b>52.7</b>	16.2	7.3	43.6	27.3
Double vision	25.5	41.2	41.2	<b>49</b>	9.8	41.2	35.3
Bowel incontinence	17.8	33.3	<b>48.9</b>	42.2	6.7	42.2	26.7
Increased interest in sex	43.9	14.6	22	<b>24.4</b>	2.4	29.3	58.5
Delusions	8.7	39.1	<b>60.9</b>	39.1	17.4	56.5	26.1

**Bold Italics** = HCP the largest proportion of patients reported symptoms to.

\* HCP = GP, PD nurse or consultant.

previous research using the NMSQuest [1–3]. The high mean number of NMS reported by each participant over a 12 month period (10.5) reinforces the importance of identifying and treating these symptoms to improve patient QoL and well-being.

Failure to disclose NMS to HCPs has been previously documented [10] and similarly high rates of non-disclosure were found in the present study. However, this research is the first to provide an in-depth analysis of NMS reporting to both formal and informal sources. A

**Table 3**  
Generalised estimating equations for barriers to help-seeking for non-motor symptoms (only significant associations shown, p < 0.05).

Barrier/NMS	Odds Ratio	Confidence interval	Wald Chi-Square	p-value	Odds Ratio	Confidence interval	Wald Chi-Square	P-value		
<b>Barrier</b>	<b>Uncertainty whether the symptom is part of PD</b>				<b>Belief that the symptom is not serious</b>					
• Urinary Urgency	.342	.137	.851	5.325	.021	–	–	–	–	
• Unexplained Pain	.125	.055	.284	24.662	< .001	.237	.098	.576	10.09	.001
<b>Barrier</b>	<b>Belief that self-help strategies are a preferable or acceptable option</b>				<b>Belief that raising the problem is not socially acceptable</b>					
• Unexplained Pain	–	–	–	–	–	.258	.089	.747	6.248	.012
• Constipation	.278	.090	.860	4.930	.026	–	–	–	–	–
<b>Barrier</b>	<b>A perception of the symptom as embarrassing</b>				<b>Communication skills</b>					
• Urinary urgency	–	–	–	–	–	.123	.015	.990	3.878	.049
• Lower libido	.177	.039	.811	4.970	.026	.074	.010	.574	6.207	.013
• Difficulty having sex	.149	.033	.671	6.155	.013	.064	.008	.490	7.004	.008
<b>Barrier</b>	<b>Acceptance of the symptom as ‘part of life’</b>				<b>Uncertainty that effective treatment is available</b>					
• Dribbling	–	–	–	–	–	6.085	1.012	36.602	3.891	.049
• Taste and smell	.109	.014	.866	4.390	.036	–	–	–	–	–
• Constipation	.064	.008	.490	7.004	.008	–	–	–	–	–
• Bowel emptying	.069	.009	.529	6.613	.010	–	–	–	–	–
• Urinary urgency	.036	.005	.267	10.562	.001	.364	.146	.911	4.661	.031
• Nocturia	.060	.008	.456	7.380	.007	–	–	–	–	–
• Unexplained pain	.027	.004	.197	12.606	< .001	.193	.083	.452	14.378	< .001
• Forgetting	.097	.012	.770	4.877	.027	–	–	–	–	–
• Sad	.069	.009	.529	6.613	.010	–	–	–	–	–
• Difficulty having sex	.047	.006	.357	8.764	.003	.390	.155	.980	4.009	.045
• Dizzy from standing	.097	.012	.770	4.877	.027	–	–	–	–	–
• Insomnia	.081	.010	.628	5.783	.016	–	–	–	–	–
• Excessive sweating	.123	.015	.990	3.878	.049	–	–	–	–	–

**Bold** = barrier under consideration.

number of significant findings emerged. Firstly, participants were likely to have discussed their symptom with a friend or family member even if they had not discussed it with an HCP. This highlights the importance of providing family members and carers with good quality information about NMS, available treatments and services. Recent research identified patient and carer dissatisfaction with the quality of information and explanation of NMS during consultations with HCPs [21]. This suggests an urgent need to provide educational resources for both patients and caregivers.

Secondly, for the majority of symptoms the largest proportion of patients reported NMS to their PD nurse rather than any other HCP. While it is positive that patients are reporting to an HCP with specialist PD knowledge, those without regular access to a PD nurse might be at greatest risk of having undisclosed NMS [22]. Gaps in PD nurse service provision are not confined to the UK and are apparent across a range of countries indicating the potentially global nature of the problem [23–25]. The larger proportion of patients reporting NMS to their PD nurse than their consultant could be attributable to a range of factors: it may reflect ease of access to PD nurses comparative to consultants, patients may feel more confident to discuss NMS with a specialist nurse or there may simply be more time available during appointments with PD nurses for discussion of a range of concerns.

A range of barriers to reporting NMS were endorsed with the most common being accepting the symptom as part of everyday life, not associating the symptom with PD and believing that no effective treatments were available. Significant associations were found between barriers to symptom reporting and individual NMS suggesting that the type of barrier preventing reporting may be specific to the symptom. Interestingly no gender differences were found in barriers to symptom reporting. Due to the predominantly white British sample we were unable to explore the effect of ethnicity on help-seeking and the associated barriers. Ethnicity is likely to play a significant role in symptom reporting for a variety of reasons including language and cultural barriers [26]. Future research is required to explore these barriers.

The findings of the present research suggest that any interventions aimed at increasing help-seeking for non-motor symptoms may be most effective if different strategies were used to target individual NMS. For example the use of normalising information and reassurance about asking for help may be helpful for patients experiencing sexual dysfunction. Normalising information and reassurance have increased help-seeking intentions for gynaecological cancer symptoms where embarrassment also acts as a barrier to accessing care [27]. Information about NMS and available treatment options may be more effective in encouraging help-seeking for unexplained pain and urinary symptoms. Supporting patients to consider the pros and cons of reporting symptoms they have ‘accepted as part of life’, such as constipation, excessive sweating and insomnia, may encourage help-seeking. Pros and cons exercises are commonly used in Cognitive Behaviour Therapy to help patients consider all perspectives and outcomes before making decisions [28]. This exercise may illustrate that reporting symptoms is relatively low cost and has the potential to lead to significant improvements in quality of life through appropriate symptom management.

Also notable from the study was the significant proportion of participants reporting moderate or low levels of distress. While this may link to symptom frequency or severity, it may also be associated with protective psychological factors. One of these may be acceptance. While acceptance of the symptom as part of PD emerged as a barrier to help seeking in those with distressing symptoms, it can be a positive adaptation in those living with a chronic condition where no symptomatic treatment is available. Evidence supports an association with better health outcomes (lower levels of depression and increased health related quality of life) in conditions such as chronic pain [29]. In the present study, low levels of distress associated with a symptom in some participants may relate to a positive adjustment to the presence of the symptoms. However, while such acceptance may be a positive or protective psychological factor for some, it still presents a barrier to help

seeking when the symptom is treatable. Indeed for all but three NMS explored in this study 100% of participants endorsing acceptance as a barrier to help-seeking were experiencing moderate to severely distressing NMS. This suggests that in the present sample acceptance acted as a barrier rather than psychologically protective factor.

The study explored a wide range of symptoms which are all known to be non-motor symptoms of PD. However we cannot say definitively that these symptoms are associated with PD rather than other comorbid conditions. Regardless of aetiology the sample reported experiencing untreated distressing symptoms. Encouraging and supporting patients to report these symptoms should enable them to receive appropriate management and potentially reduce distress and improve well-being whatever their cause.

The present study is not without limitations. The sample was recruited via two methods, outpatient clinics and the Parkinson's UK Research Network. The latter consists of people diagnosed with PD who have actively opted to participate in research projects. It is likely that these patients are proactive and knowledgeable about their condition which may have led to a lower rate of non-disclosure than may be seen in a broader outpatient clinic sample. The NMSQuest item ‘altered interest in sex’ covers both loss of interest in sex and hypersexuality. Barriers preventing help-seeking are likely to vary between these two symptoms, for example loss of interest in sex may be associated with increasing age but it seems unlikely that hypersexuality would be attributed to aging. Consequently to achieve the aims of the present study it was necessary to subdivide this item. However the NMSQuest was developed as an evaluation and not a discriminant tool [1] and consequently issues of validity and reliability are not relevant here. The barriers list was developed from qualitative research by Hurt et al. [17]. It was designed as a checklist rather than a quantitative scale and consequently no assessment of the validity and reliability was undertaken.

Despite these limitations the findings do highlight the prevalence and burden of NMS and the high rates of non-disclosure. The identification of common barriers to symptom reporting provides a basis from which to develop much needed interventions to encourage patients with untreated, distressing NMS to report them to their HCP. Increased NMS reporting should lead to receipt of appropriate clinical care potentially improving well-being and quality of life.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.parkreldis.2019.04.014>.

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