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Identifying barriers to help seeking for non-motor symptoms in people with Parkinson's disease

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Conflicts of Interest

The Authors declare that there are no conflicts of interest

Abstract

Non-motor Symptoms (NMS) of Parkinson's disease (PD) have a significant impact on quality of life. Despite this many NMS remain unreported by patients and consequently untreated. The present study explored barriers to help-seeking using two theoretical frameworks, the Common Sense Model of illness and Theoretical Domains Framework. 20 Participants completed semi-structured interviews to explore symptom beliefs and help-seeking behaviour. Uncertainty about the relationship of NMS to PD and lack of clarity around treatments were common. Embarrassment and communication difficulties were common for potentially sensitive symptoms such as sexual dysfunction. Symptom perceptions and beliefs about help-seeking acted as barriers to reporting NMS.

Key words:

ILLNESS PERCEPTIONS, HEALTH BEHAVIOUR, THEORIES, BELIEFS, HEALTH PSYCHOLOGY, CHRONIC ILLNESS

Introduction

Parkinson's disease (PD) is characterised by disorders of movement including tremor, rigidity and bradykinesia. Alongside these well recognised motor symptoms over 90% of patients experience a range of non-motor symptoms (NMS) including sleep and mood problems, hallucinations and delusions, gastrointestinal and urinary symptoms, and sexual dysfunction (Chaudhuri et al., 2007; Barone et al., 2009). Although present from the earliest stages of the disease, their burden increases systematically with disease progression (Chaudhuri and Martinez-Martin, 2008).

NMS have been found to have a greater impact on patient quality of life than motor symptoms (Hinnell et al., 2012; Gallagher et al., 2010; Martinez-Martin et al., 2011) and are reported by patients to be equally burdensome, if not more so, than motor symptoms (Politis et al., 2010).

Despite their prevalence and burden routine screening for NMS in specialist clinics remains low (Parkinson's UK, 2012). Additionally, up to 65% of patients experiencing NMS, when directly questioned, had not declared them to a healthcare professional (HCP) (Chaudhuri et al., 2010).

Several reviews outline available treatments for NMS (Miyasaki, 2006; Zesiewicz et al., 2010; Seppi et al., 2011). Pharmacological and non-pharmacological interventions can be efficacious for some NMS, while others remain understudied. Findings suggest early identification is likely to reduce symptom burden (Chaudhuri et al., 2011). Consequently many patients may be experiencing troublesome or distressing NMS for which efficacious treatments exist but non-declaration prevents access to the appropriate clinical care.

Little is understood about the factors which prevent patients reporting NMS to a HCP. A preliminary study (Chaudhuri et al., 2010) found non-declaration of NMS to be associated with a lack of awareness that symptoms were related to PD, embarrassment at discussing symptoms, and limited time in consultations for discussing non-motor issues. This information was collated from responses to a single question 'why have you not told your healthcare provider?' for each symptom endorsed on a simple self-report instrument, the Non-Motor Symptom Questionnaire (NMSQuest) (Chaudhuri et al., 2006). Use of a single question may fail to capture the complexity of barriers to symptom declaration.

Understanding factors which predict or prevent health behaviour is essential for the design of effective behavioural interventions. The Medical Research Council (MRC) framework for developing complex interventions provides comprehensive guidance for the development, evaluation and implementation of complex interventions to improve health. The framework emphasises the importance of using theory to understand determinants of behaviour and develop behaviour change interventions (Craig et al., 2008). However selecting which theory to use to guide intervention development can be complex.

Numerous psychological theories have been proposed to explain health behaviours. The Theoretical Domains Framework (TDF)(Cane et al., 2012) rationalises 33 of these theories to provide a comprehensive framework for identifying determinants of behaviour (e.g. help-seeking). The TDF consists of 14 groups of factors or 'theoretical domains' which could influence behaviour e.g. 'knowledge', 'skills', 'beliefs about consequences.' Identifying the theoretical domains which act as barriers to help-seeking will facilitate the selection of appropriate behaviour change techniques to implement in a behavioural intervention aimed at increasing symptom reporting (Cane et al., 2015).

However, while the TDF encompasses a broad range of determinants of behaviour previous research has demonstrated the importance of patients' personal understanding of illness in influencing help-seeking behaviour (Stack et al., 2012). The Common-Sense Model of Illness Perception (CSM) provides an in-depth understanding of how patients' perceptions of their health and illness can influence health behaviour. The CSM proposes that an individual's understanding of their health and illness influences the steps taken to cope with illness (Leventhal et al., 1984) The CSM explores a range of beliefs a person may hold about a symptom including 'treatment control', 'consequences' and 'timeline'. The CSM has proved a useful framework in people with PD (Hurt et al., 2014) and provides a framework which allows detailed exploration of patient perceptions of illness. In this way the CSM can be seen as complimentary to the TDF in the exploration of determinants of help-seeking behaviour.

As the first stage of developing an intervention to increase NMS reporting the aim of the present study was to identify barriers which prevented patients with PD reporting the most common and treatable NMS to their HCP using qualitative methods. An in-depth investigation of symptom reporting which explored patient beliefs about both the symptom itself and the act of help-seeking may reveal additional barriers to help-seeking for NMS. This will allow the development of targeted behavioural interventions to support and empower patients with Parkinson’s to report NMS and consequently increase receipt of appropriate clinical care.

Methods

Design

A qualitative semi-structured interview was designed to elicit beliefs about undeclared burdensome NMS Data collection took place between February 2014 and December 2014 and ethical approval was granted by the City, University of London Research Ethics Committee (Ref: Staff/13-14/10) and Cornwall and Plymouth Research Ethics Committee (ref: 14/SW/0099).

Participants

Participants were recruited through the Parkinson's UK Research Support Network or via outpatient neurology clinics at King's College Hospital and Lewisham Hospital. Eligibility was determined by participants diagnosed with idiopathic PD, and reporting at least one moderate to severe NMS that they had not previously reported to their PD HCP. The study focused on six different NMS symptom clusters (encompassing 16 different NMS) rather than all possible NMS. The reasons for this are two-fold: firstly the NMSQuest assesses 30 different symptoms and it was judged neither feasible nor necessary to conduct an in-depth exploration of all 30 symptoms. Secondly, not all of the NMS currently have efficacious treatments available. Consequently a decision was made to explore NMS which were both common and treatable. Mood problems are also common and treatable NMS however barriers to help-seeking for mood problems in PD have been explored elsewhere (Simpson et al., 2013). The recruitment target was set a priori to ensure diversity of gender and symptom presentation. Recruitment continued until there was a heterogeneous sample regarding gender and symptom presentation (24 interviews) of 2 men and 2 women experiencing one symptom from the six different clusters: (1) upper gastro-intestinal, (2) urinary, (3) bowel, (4) sleep, (5) pain and (6) sexual dysfunction. It was hypothesised that similar symptoms would be associated with similar barriers to help-seeking (e.g. urinary frequency and nocturia). Consequently patients were only asked to discuss one symptom in each interview, it was not expected that participants would experience all symptoms within a cluster. Participants reporting more than one undeclared burdensome NMS could participate in up to two interviews about two different symptoms.

Measures

Non-Motor Symptoms

The NMS Questionnaire (NMSQuest) (Chaudhuri et al., 2006) was used to assess presence of NMS in the last 6 months. Although not designed as a quantitative scale the NMSQuest has shown good discriminant validity (Chaudhuri et al., 2006). For each symptom reported as present, participants were additionally asked to rate how burdensome the symptom was on a 0-3 scale (0 = not burdensome at all, 1 = mild distress and disturbance, 2 = moderate distress or disturbance and 3 = severe distress or disturbance). Participants rating symptoms as 2 and above were asked whether they had sought help for the symptom and from whom. Rickwood and Thomas' (2012) conceptual framework was used to assess help-seeking. The framework requires that process, timeframe, source, type and concern are defined and operationalised. Process refers to the part of the behavioural process that is of interest; in this case past observed behaviour. Timeframe refers to the timeframe within which the behaviour should have taken place; this was defined as 6 months. The source of the assistance was defined as formal (e.g. medical professional), semi-formal (e.g. support group leader), informal (family or friends) and self-help (e.g. visited a website). Formal help seeking intentions and barriers to help-seeking were assessed for each burdensome symptom (concern). Patients who had previously sought help for their specific NMS from a health care professional were not included.

Severity of PD

As a proxy for disease severity, the total burden of PD symptoms was assessed using the Parkinson's Disease Activities of Daily Living Scale (PADL) (Hobson et al., 2001), a self-report measure of impairment of activities of daily living associated with PD. Scores range from 1, indicating no difficulties with day-to-day activities to 5, indicating extreme difficulties with day-to-day activities. The PADLS has shown good retest reliability (r=0.89) and higher scores correlate with increasing disease severity, cognitive impairment, depression and duration of PD (Hobson et al., 2001).

Semi-structured Interview Schedule

Using the TDF an interview schedule was developed by a consensus group of Chartered Psychologists to identify and explain the potential determinants of help-seeking behaviour for NMS in PD (Cane et al., 2012). The TDF comprises 14 theoretical domains thought to determine behaviour e.g. ‘knowledge’, ‘skills’, ‘beliefs about consequences.’ A full description of the TDF domains is presented in the supplementary files. Where relevant, participants were asked about help-seeking from the HCPs involved in providing care for their PD (e.g. consultant, PD nurse, or GP).

In addition, the CSM (Leventhal et al., 1984), was used to explore the beliefs PD patients held about their undeclared symptoms. Illness beliefs are thought to fall into nine dimensions: Identity (label given to symptoms), Cause (of the symptom), Consequences (of the symptom), Timeline Cyclical (symptom comes and goes), Timeline Acute/Chronic (how long the symptom may last), Personal Control (over the symptom), Treatment Control (over the symptom), Illness Coherence (understanding of symptom) and Emotional Representation (emotional reaction to the symptom) (Moss-Morris et al., 2002).

The interview schedule used broad questions to elicit participants’ experiences and prompts directly targeting each of the domains of the TDF and the CSM. Use of the two theoretical frameworks allowed exploration of both the act of asking for help and beliefs about the symptom itself. The interview avoided reference to symptoms as NMS to prevent bias. For example, ‘Who do you usually go to for advice and treatment when you experience symptoms such as [insert symptom being discussed]?’ (See supplementary material for full interview schedule).

Procedure

Eligible participants (i.e. those with at least one previously undeclared burdensome NMS) were identified using the NMSQuest. Participants provided informed consent to take part in a telephone interview which was audio recorded and transcribed for the purposes of analysis. Following participation in the research study patients were debriefed and provided with information leaflets about relevant NMS available from the Parkinson's UK website (http://www.parkinsons.org.uk/publications).

Analysis of Semi-structured interviews

Deductive content analysis was used to analyse the interviews. This approach was selected as the aim of the analysis was to utilise pre-existing frameworks to describe the data and identify barriers to help-seeking (Elo and Kyngas, 2008). Deductive content analysis has been previously used in the analysis of TDF interviews e.g.(Phillips et al., 2015). Interviews were coded into individual belief statements and then into domains. Each domain could include several different beliefs. Two chartered psychologists (CH and LR) independently coded two interviews into the symptom beliefs and theoretical domains and then met to establish consensus. A further three interviews were then coded. The researchers then met again to discuss and formulate a consensus coding framework and coding reliability was assessed (83% agreement). Full agreement was achieved through discussion, prior to LR coding the remaining interviews.

Results

Sample Characteristics Twenty patients with a clinical diagnosis of idiopathic PD were recruited. Demographic and clinical information is presented in table 1. Four participants experienced two burdensome undeclared NMS and completed the interview for each symptom giving a total number of 24 interviews.

INSERT TABLE 1

A total of 23 barriers to symptom disclosure were identified from the interviews (8 related to symptom beliefs and 15 related to help seeking specifically). The range of beliefs about symptoms which may act as barriers to asking for help are shown in table 2. Most commonly, patients were unsure whether their symptom was related to PD; although troublesome or distressing, symptoms were not seen as sufficiently serious; did not believe that effective treatments were available for their symptom, or believed that management might lead to an adjustment of their medication, something which they wished to avoid. Patients often reported beliefs that the symptoms could be managed by self-help and/or expressed 'acceptance' of symptoms as part of their daily lives. The cyclical nature of many symptoms 'coming and going' also appeared to prevent symptom reporting and some symptoms were often perceived to be embarrassing, again inhibiting help-seeking. A full list of the symptom beliefs with the CSM which may act as barriers to help-seeking is presented to table 3.

INSERT TABLE 2

The full list of TDF beliefs about help-seeking which may act as barriers to reporting NMS is shown in table 3. Forgetting to mention symptoms or getting side tracked during a consultation were common themes. Patients also described lacking the skills needed to address NMS with their HCP. Barriers to help-seeking often arose from the environment and available resources for example the time available during a consultation, and the perceived relationship with the doctor in question. Participants often commented that the decision about asking for help was influenced by what other problems were present and prominent at the time of their appointment.

INSERT TABLE 3

Table 4 provides an overall summary the presence of each CSM and TDF related barrier within each of the six symptom clusters. A wide variety of barriers were reported in each of the clusters. The largest number of discrete barriers was reported for bladder related symptoms and the least for unexplained pain. As may be expected emotional barriers to help-seeking such as embarrassment were more common for bowel and bladder symptoms and sexual dysfunction. Patients also reported lacking the skills to talk about these symptoms to their HCP and being reluctant to discuss them with a friend or relative in the consultation room. Contextual factors such as relationship with the doctor and social factors such as not wanting to complain were common in pain. Uncertainty about the relationship of the symptom to PD and availability of treatments, lack of time in consultations and problems with memory and concentration were common across all symptom clusters.

INSERT TABLE 4

Discussion

This is only the second study to explore and identify patient reported barriers to help-seeking for NMS in people with PD, and the first to do so using widely used theoretical frameworks to explore both the patient's beliefs (Leventhal et al., 1984) about their symptom and their beliefs about the act of help-seeking (Cane et al., 2012) to examine factors which may influence the decision to seek help for NMS.

The present study echoes the preliminary findings of Chaudhuri et al.(2010) that embarrassment, lack of awareness that NMS were related to PD, and limited time in consultations could interfere with the declaration of NMS. However the present study identified a wider variety of barriers to reporting NMS from patient interviews and highlights the importance of exploring barriers within particular classes of symptom.

For symptoms which were potentially more sensitive, such as sexual dysfunction and bowel and bladder problems, patients reported that having another person e.g. a friend or family member present in the consultation was likely to prevent them disclosing the symptom to their doctor. Supporting patients to make choices regarding their consultations such as who attends and what is discussed may help increase reporting of these symptoms. In line with findings across other health conditions (Yousaf et al., 2015) embarrassment and not being able to 'find the right words' were also significant barriers to reporting sensitive symptoms. Helping patients to improve their communication skills in a healthcare context and attempting to de-stigmatize potentially embarrassing symptoms may be key to increasing patient reporting of these NMS.

However there were some commonalities across symptoms, with uncertainty about the relationship of NMS to PD, memory and concentration difficulties, and lack of clarity around the availability of treatments common across all symptom clusters. These findings suggest a need for greater patient education about the range of possible symptoms associated with PD beyond motor symptoms, and the availability of treatments for them. Increasing health literacy, or 'knowledge and beliefs' about health and illness, has been found to increase help-seeking intentions in mental health conditions (Gulliver et al., 2012). The importance of developing patient communication skills to increase help-seeking was evident throughout interviews highlighting the need for strategies to prevent patients becoming side-tracked or forgetting to raise NMS during consultations.

It is clear from the findings of this study that a single general intervention is very unlikely to be successful in increasing symptom reporting for all NMS in all patients. Barriers to help-seeking appear to vary dependent on the symptom in question and it is likely that individual characteristics, such as confidence speaking to HCPs, would impact on propensity to ask for help. This view is supported by the wide range of barriers identified within the sample. Consequently any intervention targeting non-declaration of NMS would need to employ an individualised approach to ensure appropriate barriers are targeted for each patient. This is consistent with previous research which has indicated that psychoeducation is most effective when tailored towards the individual (Dijkstra and De Vries, 1999) and has shown promise in changing help-seeking intentions (Rimer et al., 1999; de Nooijer et al., 2004).

The use of the TDF allows the barriers to help-seeking identified from interviews to be mapped onto a number of theoretical domains of health behaviour (Cane et al., 2012). This has the advantage of enabling the development of a theoretically driven individually tailored intervention to support and empower people with PD to seek-help for NMS as recommended in MRC guidance (Craig et al., 2008). The identification of relevant theoretical domains will allow the selection of appropriate Behaviour Change Techniques (BCTs) to effectively target barriers to help-seeking (Cane et al., 2015). For example in the present study patients reported lacking communication skills to discuss symptoms with their HCP. Behavioural rehearsal and practice are suggested as appropriate BCTs to overcome barriers in the skills domain. An intervention to improve symptom reporting may involve asking patients to rehearse ways of raising important issues with their HCP.

It must be acknowledged that while the symptoms discussed in this paper are known 'non-motor symptoms' of PD we cannot be certain that the problems discussed by participants were solely caused by the disease process. The symptoms described could be the result of co-morbidities or indeed symptoms such as sleep and sexual problems could have a psychological component stemming from the challenges of living with a long term condition. Despite the multifaceted nature of causality all the participants reported experiencing moderate to severely distressing problems for which they were currently not receiving any support. Although a Parkinson's HCP might not in all cases be able to provide appropriate care to a patient reporting these symptoms it is hoped that reporting will set the patient on a path to finding adequate support and relief from their symptoms. Any intervention should incorporate a variety of self-help advice and techniques to allow patients to self-manage their symptoms if appropriate.

There are a number of limitations to the present study which must be considered. For the reasons stated, only six NMS were examined. While these covered a range of symptom domains they did not cover common problems such as depression, or serious (but frequently non-disclosed) symptoms such as delusions and hallucination. While we have drawn some inferences from the data regarding the importance of different barriers for different symptom clusters we cannot draw any generalizable conclusions from our qualitative data that could be applied to these and other NMS. We believe that it is likely that similar barriers would apply, but to gain a fuller understanding of the relationships between barriers to reporting and individual symptom clusters a larger scale quantitative exploration of barriers to help-seeking for NMS is required. Additionally, the use of a small sample limits the generalisability of the findings to the present sample and requires clarification in a larger scale study.

The present study provides the ground work necessary to support such a large scale study and lays the foundations for the development of a targeted intervention to increase help-seeking for NMS in PD and consequently receipt of clinical care.

References

Barone P, Antonini A, Colosimo C, et al. (2009) The PRIAMO study: A multicenter assessment of nonmotor symptoms and their impact on quality of life in Parkinson's disease. *Mov Disord* 24: 1641-1649.

Cane J, O'Connor D and Michie S. (2012) Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci* 7: 37.

Cane J, Richardson M, Johnston M, et al. (2015) From lists of behaviour change techniques (BCTs) to structured hierarchies: comparison of two methods of developing a hierarchy of BCTs. *Br J Health Psychol* 20: 130-150.

Chaudhuri KR and Martinez-Martin P. (2008) Quantitation of non-motor symptoms in Parkinson’s disease. *European Journal of Neurology* 15: 2-8.

Chaudhuri KR, Martinez-Martin P, Brown RG, et al. (2007) The metric properties of a novel non-motor symptoms scale for Parkinson's disease: Results from an international pilot study. *Mov Disord* 22: 1901-1911.

Chaudhuri KR, Martinez-Martin P, Schapira AH, et al. (2006) International multicenter pilot study of the first comprehensive self-completed nonmotor symptoms questionnaire for Parkinson's disease: the NMSQuest study. *Mov Disord* 21: 916-923.

Chaudhuri KR, Odin P, Antonini A, et al. (2011) Parkinson's disease: the non-motor issues. *Parkinsonism Relat Disord* 17: 717-723.

Chaudhuri KR, Prieto-Jurcynska C, Naidu Y, et al. (2010) The nondeclaration of nonmotor symptoms of Parkinson's disease to health care professionals: an international study using the nonmotor symptoms questionnaire. *Mov Disord* 25: 704-709.

Craig P, Dieppe P, Macintyre S, et al. (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 337: a1655.

de Nooijer J, Lechner L, Candel M, et al. (2004) Short- and long-term effects of tailored information versus general information on determinants and intentions related to early detection of cancer. *Prev Med* 38: 694-703.

Dijkstra A and De Vries H. (1999) The development of computer-generated tailored interventions. *Patient Educ Couns* 36: 193-203.

Elo S and Kyngas H. (2008) The qualitative content analysis process. *J Adv Nurs* 62: 107-115.

Gallagher DA, Lees AJ and Schrag A. (2010) What are the most important nonmotor symptoms in patients with Parkinson's disease and are we missing them? *Mov Disord* 25: 2493-2500.

Gulliver A, Griffiths KM, Christensen H, et al. (2012) A systematic review of help-seeking interventions for depression, anxiety and general psychological distress. *BMC Psychiatry* 12: 81.

Hinnell C, Hurt CS, Landau S, et al. (2012) Nonmotor versus motor symptoms: how much do they matter to health status in Parkinson's disease? *Mov Disord* 27: 236-241.

Hobson JP, Edwards NI and Meara RJ. (2001) The Parkinson's Disease Activities of Daily Living Scale: a new simple and brief subjective measure of disability in Parkinson's disease. *Clin Rehabil* 15: 241-246.

Hurt CS, Burn DJ, Hindle J, et al. (2014) Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease. *Br J Health Psychol* 19: 363-379.

Leventhal H, Nerenz D and Steele C. (1984) Illness representations and coping with health threats. In: Baum A and Singer J (eds) *A Handbook of Psychology and Health* Hillsdale, NJ: Erlbaum, 219-252.

Martinez-Martin P, Rodriguez-Blazquez C, Kurtis MM, et al. (2011) The impact of non-motor symptoms on health-related quality of life of patients with Parkinson's disease. *Mov Disord* 26: 399-406.

Miyasaki JM. (2006) New practice parameters in Parkinson's disease. *Nat Clin Pract Neurol* 2: 638-639.

Moss-Morris R, Weinman J, Petrie K, et al. (2002) The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health* 17: 1-16.

Phillips CJ, Marshall AP, Chaves NJ, et al. (2015) Experiences of using the Theoretical Domains Framework across diverse clinical environments: a qualitative study. *Journal of Multidisciplinary Healthcare* 8: 139-146.

Politis M, Wu K, Molloy S, et al. (2010) Parkinson's disease symptoms: the patient's perspective. *Mov Disord* 25: 1646-1651.

Rickwood D and Thomas K. (2012) Conceptual measurement framework for help-seeking for mental health problems. *Psychol Res Behav Manag* 5: 173-183.

Rimer BK, Conaway M, Lyna P, et al. (1999) The impact of tailored interventions on a community health center population. *Patient Educ Couns* 37: 125-140.

Seppi K, Weintraub D, Coelho M, et al. (2011) The Movement Disorder Society Evidence-Based Medicine Review Update: Treatments for the non-motor symptoms of Parkinson's disease. *Mov Disord* 26 Suppl 3: S42-80.

Simpson AC, Samuel M, Lawrence V, Brown RG. (2013) Seeking help for mood problems in Parkinson's: Patient and carer perspectives [abstract]. *Movement Disorders* 28, Suppl 1 :898

Stack RJ, Shaw K, Mallen C, et al. (2012) Delays in help seeking at the onset of the symptoms of rheumatoid arthritis: a systematic synthesis of qualitative literature. *Ann Rheum Dis* 71: 493-497.

Parkinson’s UK. (2012) National Parkinson's Audit Report 2011. May 2012 ed.

Yousaf O, Grunfeld EA and Hunter MS. (2015) A systematic review of the factors associated with delays in medical and psychological help-seeking among men. *Health Psychol Rev* 9: 264-276.

Zesiewicz TA, Sullivan KL, Arnulf I, et al. (2010) Practice Parameter: treatment of nonmotor symptoms of Parkinson disease: report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 74: 924-931.

Table 1: Socio-demographic and sample description (N=20)

Characteristics	**N**	**Mean (SD)**	**Range**
Age	**20**	**61.9 years (6.5)**	**49-75 years**
Male	**10**	**-**	**-**
Female	**10**		
Marital status:			
Married/Cohabiting	**15**	**-**	**-**
Single/Divorced	**4**		
Widowed			
	1		
Level of education:			
University educated	**6**	**-**	**-**
A-levels	**7**		
GCSE	**5**		
Left school pre 15 years	**2**		
Employment status:			
Retired	**16**	**-**	**-**
Employed	**4**		
Years since diagnosis	**20**	**5.5 years (4.2)**	**1-16 years**
Disability (PADL)No		**3 (1.1)**	**1-5**
difficulties	**1**		
Mild	**6**		
Moderate	**8**		
Severe	**2**		
Extreme	**3**		

Table 2. Beliefs about the symptom identified from interviews which may act as barriers to help-seeking classified by CSM domains

CSM Domains	Symptom belief	Number of interviews* (%)	Example Quote
Identity	Uncertainty whether the symptom is part of Parkinson's Disease	16 (67%)	I just wonder if any other…is this normal, is it Parkinson's related or is it age-related?
Consequences	Belief that the symptom is not serious	13 (54%)	it's slightly tedious - it's not going to kill me.
Consequences	Acceptance of the symptom as 'part of life'	7 (29%)	The trouble is it sort of becomes sort of part of your life to deal with it, and you don't see…eventually you don't see it as a problem.
Personal Control	Belief that self-help strategies are a preferable or acceptable option	12 (50%)	so I've tried to sort of keep a diary on occasions just to sort of try and work out for myself what, what triggers it to be worse and when my better days are, and you know, what I can do to you know try and ease…like I say, to try and help myself.
Treatment control	Uncertainty that effective treatment is available	19 (79%)	you sometimes think there's nothing they can do so it's not worth saying anything.
Treatment control	Concern the treatment of symptom will require change of PD medication or taking extra medication	18 (75%)	I mean I'm a little bit worried um, you know about changing the medication, so as long as, the longer I can stay on the low, lowest dose
Emotional representations	A perception of the symptom as embarrassing	11 (46%)	it's an embarrassment to me I think is the best way to

			describe it
Timeline	Fluctuating presentation	12 (50%)	It’s worse when I get tired and sometimes when I go to bed and I’m shaking, it’s difficult to get…to relax, to get to sleep, but um, there are other times it’s not too bad and I can get to sleep straight away

*The number of interviews in which this barrier was mentioned (max=24)

Table 3. Beliefs about help-seeking identified from interviews which may act as barriers to asking for help classified by TDF domains

TDF Domains	**Belief**	Number of interviews* (%)	Example quote
Skills	Communication skills	11 (46%)	it's difficult to sort of tell a doctor or tell, tell…to speak about it.
Social/ professional role and identity	Belief that it is the HCPs role to ask	6 (25%)	And they should ask. But well they say how are you feeling and you think fine. I think they should probe a bit more and not just accept it.
Beliefs about Consequences	Belief that reporting would involve seeing other HCPs	12 (50%)	What do I think'd happen? I think they'd just refer me. I seem to be referred all over the place.
Environment Context and Resources	Lack of rapport with HCP	12 (50%)	…I mean my relationship is more matter-of-fact – you know? Hello and how are you. It, it's not a…it's not a…I mean it's more business, it's not a warmth situation
Environment Context and Resources	Lack of time	16 (67%)	Time, too under time pressure, and you just don't want to hold anyone up, you know?
Environment Context and Resources	Preference to talk to different HCP (Familiarity/availability)	15 (63%)	I think I'd rather see my own [family] doctor about it
Environment Context and Resources	Preference to talk to HCP of same gender	5 (21%)	I mean the thing is that a man might understand it…er, be more understanding
Environment Context and Resources	Lack of priority to NMS in consultation	6 (25%)	I suppose the main thing I...we talk about is…is my main symptoms which is the stiffness and the rigidity and the restlessness in my leg

Goals	Not a priority at the time	14 (58%)	there's always something that's more important I suppose
Intentions	Lack of intention to report	7 (29%)	Depends how it goes. No. I tend not to think…I tend to feel most probably not.
Memory, Attention and Decision Processes	Lack of energy	5 (21%)	…you've only got enough energy in one appointment. If you had an appointment for two hours I don't think you'd get through all your list 'cos you, you'd run out of steam really.....
Memory, Attention and Decision Processes	Problems with memory and concentration	15 (63%)	sometimes it's just, it's just forgetfulness or something that's just…that, you know there's so many other things to think about.
Social influences	Belief that raising problem not socially acceptable ('complaining')	9 (38%)	I'm not a great go around and talk about your symptoms you know… stiff upper lip sort of generation still
Social influences	Presence of another non-HCP	6 (25%)	it might be embarrassing you know um, possibly yes, that's probably why I don't mention it as well 'cos when my friends' been in there with me I couldn't um, talk about urine or bowels
Social influences	Lack of interest from HCP implying lack of seriousness	5 (21%)	It, it's not, it's not picked up on as important by the specialists, so you think oh well, it's not important

*The number of interviews in which this barrier was mentioned (max=24)

Table 4

Beliefs identified in interviews according to symptom cluster (CSM and TDF)

Domains	Symptom belief	Bowel	Bladder	Sexual Dysfunction	Sleep	Pain	Upper GI
Identity	Uncertainty whether the symptom is part of Parkinson's Disease	■	■	■	▒	▒	▒
Cons	Belief that the symptom is not serious	▒	■	▒	■	▒	▒
Cons	Acceptance of the symptom as ‘part of life’	□	▒	□	▒	▒	▒
PC	Belief that self-help strategies are preferable or acceptable	▒	■	■	▒	□	■
TC	Uncertainty that effective treatment is available	■	■	■	■	■	▒
TC	Concern the treatment will require change of PD medication	▒	■	■	■	▒	▒
Emotion	A perception of the symptom as embarrassing	▒	■	■	□	□	▒
Timeline	Fluctuating presentation	▒	■	▒	▒	▒	▒
Skills	Communication skills	▒	▒	■	▒	□	▒
SPRI	Belief that it is the HCPs role to ask	▒	▒	▒	▒	□	□
BAC	Belief that reporting would involve seeing other HCPs	■	■	□	▒	□	▒
ECR	Lack of rapport with HCP	▒	■	▒	▒	■	▒
ECR	Lack of time	▒	■	■	▒	■	■
ECR	Preference to talk to different HCP (familiarity/availability)	▒	■	▒	■	■	■
ECR	Preference to talk to HCP of same gender	□	▒	▒	▒	▒	□
ECR	Lack of priority to NMS in consultation	▒	▒	▒	▒	□	▒
Goals	Not a priority at the time	▒	■	▒	▒	■	■
Intention	Lack of intention to report	▒	□	▒	▒	▒	▒
MADP	Lack of energy	▒	▒	□	▒	□	▒
MADP	Problems with memory and concentration	■	■	■	▒	▒	■
SI	Belief that raising problem not socially acceptable	▒	▒	▒	▒	■	▒
SI	Presence of another non-HCP	▒	▒	▒	□	□	□
SI	Lack of interest from HCP implying lack of seriousness	▒	▒	□	□	▒	▒
	Number of barriers	21	22	19	20	15	20

Cons – consequences, PC – personal control, TC - treatment control, Emotion – emotional representation, SPRI – Social/professional role and identity, BAC - Beliefs about Consequences, ECR - Environment Context and Resources, MADP – Memory attention and decision processes, SI – Social Influences ,

Key: Number of participants reporting each barrier (maximum of four)

0	□
1-2	▒
3-4	■

Supplementary material

The Theoretical Domains Framework (Cane et al., 2012)

Domain	Explanation
Knowledge	An awareness of the existence of something
Skills	An ability or proficiency acquired through practice
Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting
Beliefs about Capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use
Optimism	The confidence that things will happen for the best or that desired goals will be attained
Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way
Goals	Mental representations of outcomes or end states that an individual wants to achieve
Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives
Environmental Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour
Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
Behavioural Regulation	Anything aimed at managing or changing objectively observed or

	measured actions

Interview schedule

Introduction: We are interested in how people with Parkinson's make decisions about whether to tell a health professional about a problem with their health and who they would consult. I'm interested in you as a whole person, rather than focusing on Parkinson's. During the conversation I'd like to focus on just one of the symptoms you mentioned….. I'd like to start by asking you a few questions about this symptom.

Domain targeted	question	prompts
Beliefs about the symptom (CSM)	1. Can you start by telling me about the symptom that you experience? I'm interested to hear your personal views and thoughts about it.	
Identity		Do you think this symptom is related to your PD or is it something else?
Cause		What do you think causes your symptom? [*Explore identity if relevant*]
Consequences		Tell me about how the symptom affects your life?
Timeline		How long do you think your symptom is going to last?
Emotional representation		How do you feel about having…?
Personal control		Can you tell me about anything that makes the symptom better or worse?
Treatment control		What do you think can be done to help with your symptom?
Illness coherence		How do you view this symptom in relation to the symptoms of your Parkinson's?

		How does it affect your everyday life compared to other symptoms?
Beliefs about help-seeking (TDF) Now I'd like to talk about your experience of asking health professionals for help and advice about health issues. There are many different people you could approach for treatment and advice about your health such as doctors (GPs, hospital specialists), nurses and therapists. My questions refer to all these groups. I'm not suggesting who you should ask for help, I'm interested in your views.		
	1. Can you tell me about your experience of seeking advice and treatment for symptoms like this?	
knowledge		Who do you usually go to for advice and treatment when you experience symptoms such as…? [*If not PD team ask*] Would you ever think of asking someone that specialises in PD?? [Why/why not?]
[Ask the following questions about the health professional group the participant said they were most likely to go to, if this is not the PD team also ask about them. Ensure you ask about BOTH the GP and the PD team]	**[When asking questions below attempt to elicit general experiences rather than specific instances e.g. my train was delayed last time I went to clinic so I was late].**	
	2. Can you tell me a bit about what it is like when you have a consultation with *[group reported above*]?	
Memory, attention and decision making processes		What is generally going on in your head when you go to an appointment? [*Prompt*: memory, attention, decision processes]

Beliefs about capabilities		How easy do you find it to talk to health professionals about symptoms? [Why? Does that differ depending on which type of health professional you are talking to? How?]
Social identity/role		As a patient, do you think it is up to you to tell doctors/nurses/therapists about your symptoms (or should they ask you)? Do you take the initiative? [Does that differ depending on who you are talking to?? How?]
	3. Can you tell me what it is like telling [*health professional group*] about symptoms such as….? (Or what you think it would be like?)	
Skills		How would you actually raise an issue? Are there any strategies you use? [*if yes*: what?]
Emotion		When you think about telling [*health professional group*] about your symptom how do you feel? [*prompt:* fear, anxiety, before, during].
	4. What kind of things would make you more likely to tell [*health professional group*] about your symptom?	
Reinforcement		What are the things that would make you more likely to report your symptom?

Environmental context and resources		Is there anything about the consultation which would influence whether or not you mentioned….? [*prompt:* time, location, doctor/nurse/therapist(mood, interpersonal behaviour), who else is in the consultation e.g. family member].
Social influence		Would anyone else influence whether you reported your symptom? [*Prompt*: who? Family, friends, carer]
Optimism, beliefs about consequences	If you were going to tell [health professional group] about the symptom what do you expect would happen?	
		What are the benefits of telling them?
		What are the drawbacks of telling them?
		Are you optimistic about this? [*Ask if not addressed in earlier answer*]
Goals	5. Considering all the issues you may discuss at your consultation how important is it to discuss this one….? (Scale 1-10). Why?	
Intentions	6. Do you think you are going to tell a doctor/nurse/therapist about your symptoms at your next appointment? [Do you want to?]	
Behavioural Regulation	7. How are you going to make it happen? What usually stops	

	this from happening…?	
	Finally, are there any other reasons why you might not tell [*health professional*] about your symptom that we haven’t already discussed?	
	Are any of the symptoms that we talked about today ever raised during your consultations with your hospital specialist?	
	Thank you for taking the time to talk to me.	