The care needs of patients with cognitive impairment in Late-Stage Parkinson's Disease

Jennifer S. Pigott[1] MBBS (Orchid 0000-0002-0951-7941), Bastiaan R. Bloem[2] (Orchid 0000-0002-6371-3337), Stefan Lorenzl[3] MD (Orchid 0000-0002-1165-0821), Wassilios G. Meissner[4,5] (Orchid 0000-0003-2172-7527), Per Odin[6] MD, PhD (Orchid 0000-0002-0756-7478), Joaquim J. Ferreira[7] MD, PhD (Orchid 0000-0003-3950-5113), Richard Dodel[8] MD (Orchid 0000-0003-2044-6299), Anette Schrag[1] FRCP, MD, PhD (Orchid 0000-0002-9872-6680)

1. Queen Square Institute of Neurology, University College London, London, United Kingdom

2. Radboud University Nijmegen Medical Centre; Donders Institute for Brain, Cognition and Behavior; Department of Neurology; Nijmegen, The Netherlands

3. Institute for Palliative Care, Paracelsus Medical University, Salzburg, Austria and Department of Neurology and Palliative Care, University Hospital Agatharied, Germany and Institute of Nursing Science and -Practice, Salzburg, Austria.

4. CHU de Bordeaux, Service de Neurologie des Maladies Neurodégénératives, IMNc, 33000 Bordeaux, France; Univ. de Bordeaux, CNRS, IMN, UMR 5293, 33000 Bordeaux, France

5. Dept. Medicine, University of Otago, Christchurch, and New Zealand Brain Research Institute, Christchurch, New Zealand

6. Division of Neurology, Department of Clinical Sciences Lund, Lund University, Skåne University Hospital, Lund, Sweden

7. Instituto de Medicina Molecular João Lobo Antunes, Faculdade de Medicina, Universidade de Lisboa, Portugal

8. Department of Geriatric Medicine, University Duisburg Essen, Essen, Germany

Corresponding Author:

Prof Anette Schrag

Email: a.schrag@ucl.ac.uk

Telephone: 020 7679 2000 extension 68135

Mailing address:

Clinical Neurosciences,

University College London,

Royal Free Hospital

Rowland Hill Street

London, NW3 2PF

UK

Submitting Author:

Dr Jennifer S. Pigott

Email: j.pigott@ucl.ac.uk

Abstract

Background

Cognitive impairment is common in Parkinson's disease (PD), but care needs and resource use for those with significant cognitive impairment are not well established.

Methods

675 participants with PD from the international Care of Late-Stage Parkinsonism (CLaSP) study were grouped into those without (n=333, 49%) and with cognitive impairment (MMSE<24/30 or diagnosis of dementia or Mild Cognitive Impairment; n=342, 51%) and their clinical features, care needs, and healthcare utilisation compared. Regression models were built to investigate predictors of recent healthcare consultation across the whole sample.

Results

Cognitive impairment was associated with more motor and non-motor symptoms, less antiparkinsonian but higher rates of dementia and antipsychotic medications, worse subjective health status and greater caregiver burden. A significant proportion did not have a pre-established cognitive diagnosis. Care needs were high across the whole sample but higher in the cognitively impaired group. Home care and care home use was higher in the cognitive impairment group. However, appointments with healthcare providers were similar between the groups and significantly fewer participants with cognitive impairment had had recent PD Nurse consultations. Worse cognitive impairment and more severe symptoms of depression or apathy, as well as care home residence were associated with lower frequency of recent healthcare consultation, although this varied by profession.

Conclusions

Those with cognitive impairment have more severe PD, higher care needs and greater social care utilisation than those with normal cognition, yet use of health care services is similar or less. Cognitive impairment and care home residence appear to be barriers to healthcare utilisation. This challenges current models of care. We propose that alternative models of care may be required to serve this population.

Plain Language Summary

Parkinson's disease is a long-term progressive health condition. Over time, many people with Parkinson's develop problems with thinking and memory, called cognitive impairment. This can negatively impact the daily lives of the person with Parkinson's and their caregiver. It is also thought to be a barrier to accessing healthcare. How people with Parkinson's who have cognitive impairment use healthcare and detail of their care needs is not well known.

We analysed data from a large sample of people with advanced Parkinson's from six European countries to investigate their symptoms, care needs and healthcare use. We compared those with cognitive impairment (342 people) to those without cognitive impairment (333 people). We also looked at associations of cognitive impairment with healthcare use across the whole group.

We found that those with cognitive impairment had more severe Parkinson's across a range of symptoms compared to those without cognitive impairment. They also had more care needs reported their health status to be worse, and their caregivers experienced greater strain from caring. Whilst use of other healthcare services was similar between the two groups, those with cognitive impairment were less likely to have recently seen a Parkinson's nurse than those without cognitive impairment. People living in care homes were less likely to have seen a Parkinson's specialist doctor

or primary care doctor. People with low motivation were less likely to have seen a primary care doctor. People with low mood were more likely to have seen a Parkinson's specialist doctor but less likely to have seen a Parkinson's nurse. People with more difficulties in their daily activities and more problems with perception (such as vivid dreams or hallucinations) were more likely to have seen a therapist.

This findings highlight unmet need. We suggest that healthcare should be more targeted to help this group of people, given their higher care needs.

Keywords

Parkinson's disease; cognitive impairment; dementia; care needs; healthcare

Introduction

Cognitive impairment is common in Parkinson's disease (PD) with prevalence of Mild Cognitive Impairment (MCI) around 40%[1], and of Parkinson's Disease Dementia (PDD) around 25%[2]. MCI is a risk factor for PDD, with increased likelihood of conversion over time, although the course of cognitive impairment in PD varies[3,4]. It is known that global disability progressively increases as cognition declines across the cognitive spectrum, even prior to the diagnosis of dementia[5,6]. MCI in PD is associated with older age, lower education, longer disease duration, higher levodopa equivalent daily dose, and more severe motor symptoms[1]. Neuropsychiatric symptoms are common and often multiple in PD[7], and hallucinations and delusions are increased in those with cognitive impairment[8,9]. More advanced cognitive impairment and PDD also often involves behavioural changes and aberrant perceptions[10] and is a key indicator of advanced PD. It is associated with reduced quality of life in patients and high caregiver burden[5], and more severe cognitive impairment is associated with nursing care home admission[11]. The economic costs of care in both dementia and PD are significant, and costs in PD increase with advancing disease[12–14] and evolution of cognitive impairment[15,16]. The care needs of patients with cognitive impairment in late-stage PD are therefore likely to be considerable and higher than those without cognitive impairment. However, no studies have specifically examined care need in those with associated cognitive impairment in late-stage PD. Understanding the care needs of this population, and their utilisation of health and social care is important for the development and delivery of appropriate services.

In PD, a wide range of barriers to healthcare access are recognised, both person-level and system-level[17]. Poor health literacy, poor patient-healthcare provider communication, poor coordination between healthcare settings and lack of availability of mental health and rehabilitation services have been reported as the overarching barriers. Acceptance of and awareness of non-motor symptoms, as well as beliefs about treatment efficacy, are barriers to help-seeking for non-motor symptoms in PD[18]. Reported barriers to mental healthcare utilisation in PD, include patients normalising symptoms,

doctors being insensitive to PD-related issues, limited availability of high quality services and physical impairment, with practical issues perceived as future barriers[19]. Cognitive impairment can interfere with participation in physical activities; self-administration of medication; understanding medical information; making treatment decisions; expressing needs and wishes and advocating for oneself; all impacting health management[17]. These cognition-related barriers were identified through qualitative studies and through quantitative studies of medication adherence. Little has been reported about the relationship between cognitive impairment and health and social care use more broadly. A small study of costs of PD found that dementia was associated with more social services use and nursing home stays, but not in-hospital stays and PD medication[15]. More detailed and larger sample data analysis is warranted to further understand the relationship between cognitive impairment and health and social care use in PD, in order to guide service design for the future.

Here in this study, we examined the clinical features, the care needs and overall health status and carer burden, as well as associated health and social care received in those with compared to those without cognitive impairment in a large sample of patients with late-stage PD. We hypothesised that those with cognitive impairment in late-stage PD would have a higher degree of disease burden and care needs, greater reduction in Hr-QoL, and that there would be higher carer burden and use of healthcare resources in the population of patients with cognitive impairment in late-stage PD.

Methods

We analysed data from the Care of Late-Stage Parkinsonism (CLaSP) study, a multi-centre, prospective cohort study of people with late-stage Parkinsonism and their caregivers over 18 months, conducted in six European countries. Details of the study have been published previously[20]. In brief, patients with late-stage parkinsonism were recruited from a range of different settings, including primary and secondary care, community settings and patient organisations, adapted to

healthcare arrangements in each country. Ethical approval was granted locally for each site, and participants provided written consent.

Participants

People with Parkinsonism, disease duration of seven years or more, and Hoehn and Yahr stage IV or V or Schwab and England stage 50% or less in the "On"-state, who did not have secondary parkinsonism or clear onset of dementia before motor symptoms, were included in the overall CLaSP study. For the present analysis we excluded participants with atypical parkinsonian syndromes, vascular parkinsonism, and those missing diagnostic information, but included those not reaching the threshold for disease duration of at least 7 years since our focus was on cognitive impairment. The countries comprised Germany (n=175), UK (n=140), Portugal (n=108), Sweden (n=106), France (n=75), the Netherlands (n=71).

Participants were allocated into two groups: those with and without cognitive impairment. Cognitive impairment was operationally defined by either a pre-established clinical diagnosis of dementia or mild cognitive impairment or a Mini Mental State Examination (MMSE) score of less than 24/30 at baseline assessment. This cut-off was chosen as a marker of cognitive impairment as it is a widely used screening threshold for dementia[21] and the detection of MCI is less well defined. Participants with an MMSE score of <24/30 who also scored 4 on the UPDRS Part-I Question-3 ("Sustained depression with vegetative symptoms and suicidal thoughts or intent") were not included since this we suggests marked depressive symptoms likely to interfere with performance on the cognitive testing.

Assessments

Data collection was by trained researchers, through face-to-face interviews with patients and their caregiver, with breaks and repeated visits as required to facilitate completion. For participants who

experienced fluctuations, assessments were undertaken in the "on" state where possible. Demographic information included gender, age, years of education and martial status. Disease information included year of PD onset, Hoehn & Yahr stage[22] and medication. Levodopa Equivalent Daily Doses (LEDD) were calculated from reported medication[23]. Parkinsonism was assessed through the Unified Parkinson's disease Rating Scale (UPDRS)[24] four parts: Mentation, Behavior and Mood (part I), Activities of Daily Living (ADLs) (part II), Motor Examination (part III), and Complications of Therapy (part IV), where higher scores indicate more severe disease. Cognition was evaluated through the MMSE[25], Clock Drawing task[26], Verbal Fluency and the Pill Questionnaire[27] (for the first three lower scores indicate greater impairment, for the latter, higher scores indicate greater impairment). the Geriatric Depression Scale (GDS)[28] (higher scores indicate more severe depression) and the Non-Motor Symptom Scale (NMSS)[29] (reflecting severity and frequency; higher scores indicate greater burden of non-motor symptoms) evaluated other non-motor symptoms.

A resource utilisation questionnaire[30] included a series of questions on care needs as well as questions about consultations with multidisciplinary primary and secondary healthcare, and formal and informal care received. Care needs were assessed on seven individual daily activity tasks: dressing, personal hygiene, food preparation, eating, medication, chores, and mobility. Dependence on others was recorded according to the Schwab and England scale[31] (ranging from 0-100%, higher scores indicate greater independence). Subjective Health Status was assessed using the EuroQoL (EQ-5D-3L)[32,33]. This is composed of five domain questions which we dichotomised into 'some problems' and 'no problems'; a summary index synthesising the 3-level responses to each question based on UK value sets[34] and a visual analogue scale for self-imagined health status (for both, lower scores indicate worse HR-QoL). Impact on caregivers was assessed by means of the Zarit Burden Interview[35], where higher scores indicate greater burden.

Analysis

Statistical analysis was performed in Stata 17[36]. Descriptive analyses of demographic and clinical information as well as care needs and healthcare utilisation were conducted, presented as mean ± standard deviation (SD), median and interquartile range (IQR) or percentages. Missing data were excluded but reported for each scale. Normality was assessed visually. Comparisons between the two groups were conducted using *t*-tests, Mann-Whitney tests and Chi-squared tests according to data type. Threshold for statistical significance was set at 0.05. Due to high proportions of missing data for the resource utilisation questionnaire, a sensitivity analysis was performed including only participants who had completed this questionnaire.

To investigate factors associated with health consultations multivariable logistic regression for the binary healthcare utilisation outcomes (if consultation had occurred in the preceding 3 months) was conducted with independent variables selected based on univariate associations with $p<0.1$ for any type of consultation, with UPDRS part-III also included due to clinical importance. UPDRS part-I questions were used individually. UPDRS part-I question 1 was omitted due to overlap with the MMSE, and the NMSS was not included due to overlap with the UPDRS. Part-I Question-3 was used as a marker of depression rather than the GDS due to a high proportion of missing data for the GDS and to ensure consistency with other features of PD on the UPDRS. UPDRS Part-IV (complications of therapy) was not included as an independent variable since it could represent an outcome of healthcare input. Variance inflation factors were checked to exclude collinearity.

Results

Participant Characteristics

Out of the total 689 participants, eleven participants were excluded due to missing MMSE data and three scored <24 on the MMSE, but also scored 4 on the UPDRS Part-I Question-3so could not reliably be categorized. Of the remaining 675 participants, there were 342 with cognitive impairment and 333 with normal cognition. In the cognitive impairment group, 243 had a pre-established

dementia diagnosis, one had a pre-established MCI diagnosis and 98 did not have a pre-established cognitive diagnosis but had MMSE<24/30. 201 participants (29%) experienced fluctuations. A small minority (2%) of participants were in an 'off'-state during assessment (7 in normal cognition group, 10 in cognitive impairment group). The majority of participants (97%) had a PD duration of >7yrs, and those that did not (n=10 in normal cognition group, n=9 in cognitive impairment group) had other markers of late-stage disease: either Hoehn & Yahr stage IV-V or ≤50% on Schwab and England.

There was a small male preponderance in both groups, more so in the cognitive impairment group but the difference between groups was not statistically significant. The cognitive impairment group was older (mean 77.83±7.70 years compared to 74.01±8.85 years, $p<0.0001$) with fewer years of education (mean 9.3±4.1 years compared to 10.74±3.72 years, $p<0.0001$). The majority of participants were married (65% in cognitive impairment group, 60% in normal cognition group) or widowed (24% in cognitive impairment group, 22% in normal cognition group). Demographic data is provided in Supplement 1.

Table 1: Clinical Features

Table 1 displays the clinical findings for the two groups, illustrating that those with cognitive impairment had more severe PD with higher UPDRS scores (parts I-III, $p<0.0001$) and NMSS scores ($p<0.0001$). Greater impairment was seen across all cognitive assessment instruments in the cognitive impairment group. Depression scores were higher in the cognitive impairment group (GDS, $p=0.0007$), though with a high proportion of missing data. Within the NMSS, scores were higher in the cognitive impairment group for all domains but for Miscellaneous (similar between the groups) and the difference for Sleep & Fatigue was not statistically significant as illustrated in Figure 1, with full data provided in Supplement 1.

Figure 1: Box Plots for Non-Motor Symptoms Scale Domain Scores, Comparing Cognitive Groups

Figure abbreviations: Cardio.= Cardiovascular; Sleep= Sleep & Fatigue; Memory= Memory & Attention; G.I.= Gastrointestinal; Sex.= Sexual function; Misc.= Miscellaneous. Scores are indicated as a percentage of maximum possible score for that domain.

The cognitive impairment group were taking lower total doses of dopaminergic medication (median LEDD 750mg, IQR 500-1050 compared to 894.97mg, IQR 560-1300, $p=0.0008$) and were more likely to be on dementia medication (40% compared to 9%, $p<0.001$): rivastigmine, donepezil or memantine. Of those with a pre-established dementia diagnosis, 43% were on dementia medication, compared to 30% of those with impaired MMSE but without a diagnosis of cognitive impairment ($p=0.015$). Out of the 177 participants with MMSE scores of ≤20/30, 81% had a pre-established diagnosis of PDD, and 19% did not. The cognitive impairment group were significantly more likely to

be on antipsychotic medication: clozapine (16% compared to 4%) and quetiapine (22% compared to 7%) ($p<0.001$).

Care Needs and Subjective Health Status

As detailed in table 2, caregiver burden, care needs and dependence were high across the whole sample but greater for the cognitive impairment group. Overall independence as indicated by the Schwab and England Scale was lower for the cognitive impairment group: median 30% (IQR 20-40), corresponding to "With effort, now and then does a few chores alone or begins alone. Much help needed" compared to 40% (IQR 30-50), corresponding to "Very dependent. Can assist with all chores, but few alone" in the normal cognition group ($p<0.0001$). Subjective health status was poorer for the cognitive impairment group on both the Visual Analogue Scale and the Summary Index (dimension scores provided in supplement 1).

Table 2: Care Needs and Subjective Health Status

Greater need for assistance was seen for the cognitive impairment group across all care activity tasks (Figure 2 and Supplement 1). Between-group differences were statistically significant for all assessed care needs (dressing $p<0.001$, personal hygiene $p<0.001$, food preparation $p<0.001$, eating $p<0.001$, medication $p<0.001$, chores $p=0.006$ and mobility $p=0.001$) with biggest difference seen for assistance with medication (preparation, intake or application).

Figure 2: Pie Charts of Care Needs by Cognitive Group

Resource Utilisation

There were high proportions of missing data for this survey. Those with lower MMSE scores and higher total UPDRS scores were more likely to be missing this survey. There were no significant differences between the cognitive groups in whether or not the participant had consulted their primary care physician (p=0.104), a neurologist or geriatrician (p=0.058), or a therapist (including physiotherapy, massage, occupational therapy, speech training and general nursing; p=0.138) for PD in the preceding 3 months (Figure 3). Relatively few participants in either group had had PD nurse consultations but fewer in the cognitive impairment group (13% in the cognitive impairment group, 19% in the normal cognition group, p=0.039). On the other hand, approximately a quarter in each group had been hospitalised for PD in the preceding three months. The absolute numbers of consultations in the preceding three months were also low across both groups, but the statistical difference for PD nurse consultations remained (see supplement 1). From both groups, very few participants had had consultations with a psychiatrist (2% both groups) or psychologist (3% cognitive impairment group; 2% normal cognition group). No participant in either group had received counselling.

Figure 3. Bar charts showing number of participants from each cognitive group who had received consultation for PD in the preceding 3 months, by healthcare profession.

Those in the cognitive impairment group were more likely to be in a nursing home or similar (37% compared to 15%, p<0.001 (table 3), and more likely to live with a family caregiver if living in their own home (72% compared to 59%, p=0.003). Family caregivers were predominantly spouses for

both groups (54% cognitive impairment group, 50% normal cognition group), but a greater proportion of daughter or son caregivers were seen in the cognitively impaired group (22% compared to 12%, $p<0.001$). For those living in their own home, more in the cognitive impairment group had had professional care and they received more hours of informal care, but there was relatively little use in either group.

Table 3: Formal and Informal Care Utilisation

Sensitivity Analysis

In analysis of only participants who had completed the resource utilisation questionnaire, the demographic, clinical, subjective health status and caregiver burden patterns remained similar and statistically significant differences remained for the same variables (Supplement 2).

Predictors of Healthcare Consultations

Predictors of health consultation utilisation varied by profession as shown in Table 4. Presence of apathy was negatively and living in their own home was positively associated with seeing a primary care physician. Presence of depression markers and living at home with or without a caregiver were positively associated with having seen a PD specialist. Presence of depression markers and more severe cognitive impairment were negatively associated with recently having seen a PD nurse. Lower age, better cognition, presence of percentual disturbances and greater disability were positively associated with therapy consultations. The low rates of mental healthcare resource utilisation precluded them from regression analysis.

Discussion

The CLaSP study provides new insight into the difficult-to-reach group of people with late-stage PD, including around half with cognitive impairment. As hypothesised and consistent with previous studies[1,5], cognitive impairment was associated with older age and more severe disease both in motor and non-motor aspects, with scores indicative of clinically meaningful differences between the groups[37], as well as increased caregiver burden and reduced subjective health status. Our detailed exploration of care activities highlights the significant and complex care needs for those with cognitive impairment in PD, with more need for assistance seen across all seven of the evaluated daily tasks compared to those without significant cognitive impairment. Despite this, and contrary to our hypothesis, healthcare consultation was *not* greater for those with cognitive impairment and *better* cognitive function was actually associated recent PD nurse consultation and recent therapy consultation.

Differences in medication management were seen between those with and without cognitive impairment. Higher rates of medication for dementia and psychosis were seen in those with cognitive impairment, whilst levodopa equivalent doses were lower in those with cognitive impairment. There is evidence for improved quality of life with dopaminergic medication[38] but symptoms in late-stage PD are seen to be less dopa-responsive[39]. We do not know from this observational study if the patients are under-treated or if the lower doses simply reflect the delicate balancing act in this context, weighing the negative effects on cognitive or psychiatric functioning against beneficial effect on motor function[40,41]. More of those with cognitive impairment were on dementia medication than those without cognitive impairment but rates were still relatively low (40%), even for those who had pre-existing diagnoses of dementia (43%). Within the cognitive impairment group, nearly a third (29%) did not have a pre-established cognitive diagnosis, and even when applying a MMSE threshold of 20/30 to identify cognitive impairment, 20% did not have a pre-established cognitive diagnosis. Underdiagnosis of PDD is a recognised issue[42]. Participants were

more likely to be on dementia medication if they had a dementia diagnosis. There is evidence for improved cognition and global function with cholinesterase inhibitors in PD[43], though adverse effects are not uncommon. European and UK guidelines recommend cholinesterase inhibitors in PDD[44,45]. However pharmacological therapy is less likely to be offered if the diagnosis of dementia is not made.

Greater need for assistance was seen for the cognitive impairment group across all seven care activity tasks, but the difference was smallest for mobility and chores, and greatest for medication, followed by personal hygiene, food preparation and eating. This is not surprising given the nature of the tasks but important since medication regimes can become more complicated and require more frequent dosing with advancing disease, which can be a challenge for care delivery, particularly for those not living with a caregiver. As expected, given the increased care need, those with cognitive impairment were more likely to be in a nursing home, and if in their own home, more likely to live with an informal caregiver, with more professional and informal care.

However, despite the higher degree of impairment, complexity, lower subjective health status and carer burden, there was no difference in frequency of primary and secondary care consultations or therapy consultations for PD, and those with cognitive impairment in fact had fewer PD Nurse consultations than those without cognitive impairment. Furthermore, across the whole sample, worse cognitive function was a significant predictor of *not* having seen a PD nurse or therapist for PD in the preceding 3 months, even when controlling for residential setting, age, and physical and functional disability, suggesting that cognitive impairment itself can be a barrier to healthcare utilisation.

Reasons for healthcare utilisation not increasing with cognitive impairment and increased care needs are not clear but are likely multifactorial. It is possible that healthcare resource capacity is not sufficient to increase with need, or it could be that these patients do not or are unable to access the available resources e.g. due to difficulties navigating healthcare systems or remembering appointments[46]. Patients with advanced PD are often seen to withdraw from specialist care[39]. In the dementia field, alongside personal factors (patients, carers and professionals), healthcare access is challenged by difficulties navigating services, inflexibility of services, fragmented care, limited knowledge and skills of professionals, poor communication and information sharing, culture of care, and ineffective healthcare policies[47–49]. Qualitative evaluation of a UK sample from the CLaSP study found that healthcare services required people with PD to 'fit-in' to service structures that did not always accommodate their complex needs[50]. It is also possible that healthcare providers as well as patients and caregivers perceive little benefit in PD-related outpatient care as currently provided. Therapeutic nihilism is reported in dementia[51,52], despite evidence for benefit from multidisciplinary therapies[53–55]. Lack of expected benefit by referring clinicians or therapists themselves could contribute to reduced healthcare utilisation, which therefore needs to be challenged.

Other psychiatric symptoms, known to be associated with cognitive impairment[9], also appear to play a role in utilisation of healthcare consultations. Lower motivation was associated with not having seen a primary care physician, but was not significant for PD-specific professionals, which could reflect the effect of apathy on help-seeking since primary care is typically utilised through patient request, whereas PD services may be more routinely scheduled. Increased severity of depressive symptoms was also associated with lower frequency of having recently seen a PD nurse but higher frequency of PD specialist consultation, perhaps reflecting the greater impairment of quality of life. Perceptual disturbance was associated with greater consultation of therapists, which may reflect the requirement for close monitoring of antipsychotic medications such as clozapine. The very low

frequency of psychiatric and psychological consultations and absence of counselling consultations across the whole sample may indicate limited availability of mental health services or under-recognition of and under-referral for psychiatric symptoms, which is a known issue[56]. Thus, identification of psychiatric symptoms is important, both in order to treat them, but also to recognise their potential impact on healthcare access.

Our regression models of healthcare consultation utilisation showed that care home residents were far less likely to have recently seen a PD specialist or primary care physician, suggesting challenges for healthcare provision in this setting. Past study has suggested there may be under-treatment of PD in care home residents[57] so finding an approach that facilitates medical input for care home residents is vital.

Having a PD specialist physician manage PD and PD nurse contact has been associated with better health-related quality of life in late-stage PD without dementia[36], yet we have identified potential barriers to these services. Our findings therefore raise questions about current healthcare delivery but also offer a potential means of improving quality of life for this population: through targeting healthcare to where the need is greatest. We propose that alternative models of care may be required to serve this underserved, complex population. In the dementia field, facilitators to service use include an "expert" point of contact[48], and areas of good practice for end of life care in dementia include specialist palliative care nurse support and in-reach to nursing homes[49], which may be relevant for cognitive impairment in PD too. Services need to take a more proactive approach to reach patients with the greatest need and offer additional support to engage with healthcare in the context of cognitive impairment. In PD more broadly, there is evidence for integrated outpatient care[58] and integrated palliative care[59] to improve quality of life and caregiver burden. A pragmatic approach, with movement disorders expert management recommendations by letter to primary care physicians, has

been tested in those with undertreated late-stage Parkinsonism and found to improve quality of life[60]. However, delivery was limited by incomplete or lack of implementation of recommendations: Barriers included inability to reconcile patient preferences with recommendation, lack of time and lack of improved outcome expectancy. Community services have more suitable infrastructure to provide accessible care; however since the evidence supports specialist input in this complex disorder, and a collaborative approach is therefore likely necessary. Integration of specialist and community services could facilitate more reliable implementation of expert advice. This could perhaps be operationalised through community geriatric medicine, community PD specialist nurses or utilise other community-based clinicians from relevant backgrounds, such as mental health or palliative care, with additional PD training. Although in the present study we have distinguished two groups, cognitive impairment exists along a continuous spectrum. A one-size-fits-all approach is unlikely to solve the issue and services need to be flexible to tailor to the needs of the individual, delivering patient-centred care[61] that recognises the challenges of cognitive impairment.

Strengths & Limitations

This study has a large and geographically widespread sample of participants from a difficult-to-reach group. As is expected with this population, missing data was high for some assessments, particularly on care needs and resource utilisation. Sensitivity analysis confirmed the patterns persisted when those with missing resource utilisation questionnaires were excluded, and it is likely that those missing this data had even less support. There was insufficient information to formally apply diagnostic criteria for MCI and PDD in PD for the whole sample, so we cannot formally report the rate of missed diagnoses. Here we have used MMSE as a marker of cognitive impairment but must recognise the limitations of this as it can represent a range of cognitive function, and indeed people can have relatively high MMSE scores even with dementia[62]. Similarly, we recognise limitation in using the UPDRS Part-1 Question-3 as a *marker* of depression, rather than a diagnosis. The

recruitment from multiple countries is a strength of the CLaSP study, though since different recruitment strategies were utilised in different countries, comparisons between countries are not appropriate.

This study invites future research to further explore why healthcare utilisation does not increase with increased needs, for example, whether the resources are not available, not accessible or not appropriate. Our analyses were also large descriptive and further studies should explore other factors that influence the need for access to health care resources. More research is needed to understand patterns of healthcare use for mental health. The study also shows a need for further exploration of alternative proactive models of care for those with complex needs, such as cognitive impairment in PD.

Conclusion

Those with cognitive impairment have more advanced PD and higher care needs than those with normal cognition, yet this is not matched by healthcare use. Care home residence appears to be a barrier to primary care and PD specialist consultation. This challenges current models of care, suggesting that healthcare needs to be targeted to those with most need. Furthermore, it highlights a need for improvement in diagnosis of cognitive impairment to offer treatment and tailor care accordingly.

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Ethical approval:

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the study. If patients were unable to provide consent, consent was obtained with the legal representative, in accordance with national law.

Conflict of Interest:

The authors declare that there are no conflicts of interest relevant to this work.

Data Availability:

Data available upon request.

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