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Experience of care for Parkinson's disease in European countries: A survey by the European Parkinson's Disease Association

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Running title: Experience of Care in Parkinson's Disease

Keywords: Parkinson's disease; patient-reported outcome; satisfaction; care; patient experience

Abstract:

Background: Few studies report on experience of care for Parkinson's disease (PD) from patients' own point of view.

Methods: Analysis of a survey in 11 European countries on self-reported access to services and satisfaction with different aspects of care.

Results: 1,775 people with PD (PwP) participated with disease duration ranging from <1 to 42 years. Initial referral to specialists had taken <3 months in most but medication reviews occurred every 3 months in only 10%, every 6 months in 37%, once a year in 40%, and every two years or less frequently in 13%. Waiting times to therapists were usually at ≥ 4 months.

Satisfaction with care was highest for involvement of PwP in decisions (63% of respondents satisfied) and involvement of family/carer (62%) followed by communication with PwP (57%), information received (54%), frequency of treatment reviews (52%), suitability of treatment for the individual condition and circumstances (52%), but lowest for availability and accessibility of treatment when needed (48%) and collaborations between healthcare professionals in delivering care (41% satisfied). The main factors associated with overall satisfaction scores with care were the overall satisfaction with initial consultation ($r=0.26$, $p<0.0001$), the sensitivity with which the diagnosis was communicated, the quantity of

information provided (both $r=0.24$, $p<0.0001$) and the frequency of medication review ($r=0.17$, $p<0.0001$).

Conclusion: More coordinated and responsive care, tailored to the individual, with regular and timely medication reviews and treatment referrals, is likely to improve satisfaction with care in current health care pathways.

Introduction

There is an increasing emphasis on patient experiences of care in health care systems (1;2), which may inform provision of care to meet the needs of patient populations. In Parkinson's disease (PD) satisfaction with care is also associated with better quality of life (3;4).

However, there is currently limited information on patients' experiences of care and areas of unmet needs from the patients' point of view in PD. "My PD Journey" is an initiative by the European Parkinson's Disease Association (EPDA) to identify current gaps in Parkinson's care from the point of view of people with Parkinson's (PwP; <http://www.epda.eu.com/get-involved/my-pd-journey/>). We here report the experience of, and satisfaction with, different aspects of care across 11 European countries from a large quantitative survey in the "My PD Journey" project.

Methods

A survey was conducted between 1st November 2014 and 12th January 2015 through the EPDA's national patient organisations in PwPs from eleven countries (Denmark, France, Germany, Hungary, Ireland, Italy, Netherlands, Slovenia, Spain, Sweden, and UK). Patients who volunteered to participate completed a self-report online survey on their experiences of care pathways (except in Slovenia where, due to low Internet access, hard copies of the survey were distributed via the national Parkinson's Association to their members).

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Measures

The survey questions were drafted based on a stakeholder meeting of EPDA members from 30 European countries, and aimed to gather information about the current state of the Parkinson's care pathways in the eleven countries. The original survey was developed in English, with the language designed to ensure that the survey would not elicit biased responses by the way the questions were phrased. The survey questions were translated into equivalent meaning in each country's language. The draft questionnaire was reviewed by members of the International Parkinson and Movement Disorders Society European Section and EPDA members from the participating European countries to ensure it covered the main relevant areas. The survey was pre-tested with a selected group of PwPs (of differing ages and years since diagnosis), to ensure that the survey questions were interpreted correctly.

The final version of the questionnaire included questions on demographics, residency, employment and disease duration, self-rated Schwab and England disability, type of healthcare professionals seen, waiting times and treatments given, frequency of medication reviews, information received and experiences of and satisfaction with health care. Frequency of medication review was collected by type of healthcare professionals with the following answer options: 'every 3 months', 'every 6 months', 'once a year', 'once every two years or more', 'do not know' and 'does not apply'. Information received was collected by type of information (symptoms, diagnosis and causes of PD, medication, surgical treatments, non-drug treatments, maintaining physical and emotional wellbeing, financial help available, support organisations, support for carers, where to find more information on PD, and taking part in clinical trials), and a summary score created for quantity of information provided. Satisfaction with care was assessed in relation to i) care received from nine different clinical professions (general practitioner or family doctor, hospital doctor, general neurologist, care of the elderly doctor (geriatrician), neurologist who is a specialist in Parkinson's, Parkinson's

nurse specialist (PDNS), physiotherapist, occupational therapist (OT), speech and language therapist), ii) eight different aspects of care (How often your treatment plan is reviewed, The way professionals communicate with you about your condition and treatment options, The information you have received from healthcare professionals, Your level of involvement in decisions about your treatment, Your family's/carer's level of involvement in decisions about your treatment, The availability and accessibility of suitable treatment options when you need them, The suitability of your treatment for your condition and circumstances, The way the various professionals work together to deliver your treatment and care). Participants were also asked about satisfaction with initial diagnostic consultation and sensitivity of communication of diagnosis. All responses were rated on a Likert scale from 1 ('very dissatisfied') to 5 ('very satisfied'), except sensitivity of diagnosis, which was measured from 1 ('not at all sensitively') to 4 ('very sensitively'). Answers of 'does not apply' were treated as missing data.

As this was a survey by a patient organisation on care experiences, no ethics committee review was required. Informed patient consent was not applicable for this study.

Data analysis

Descriptive results are presented with total numbers and percentages and mean with standard deviation (SD) or median (range), if not normally distributed. Data were tested for normality using the Kolmogorov-Smirnov Test. Principal components analysis was conducted on the 8 items on satisfaction with aspects of care to determine if a summary score for this item could be created. As all items of the eight aspects of care loaded on one factor with small differences between the factor loadings (see supplementary material, table 1), a total score for

overall satisfaction with care was created as an average of all items on aspects of care (range 1 - 40).

Correlations between variables were examined using bivariate Pearson correlations, and independent samples Chi-square and t-tests were calculated to explore any significant differences between groups. For data that were not normally distributed, non-parametric alternatives were used i.e. Spearman correlations, Kruskal-Wallis H and Mann-Whitney U tests using a significance level of 5%. Comparisons between countries were adjusted with the Bonferroni correction for multiple comparisons between 11 countries and the type of health care professionals. All analysis was conducted using SPSS (version 21).

Results

Participants

1,775 adults (958 males, 817 females) participated with an average age at diagnosis of 58 (range 25 to 90; table 1). Years since diagnosis spanned from less than one year to 42 years (figure 1). A large proportion of the sample was from Sweden (46%), and we therefore conducted a sensitivity analysis of the sample excluding the Swedish sample. The Swedish population had an earlier age of onset (56.7 years vs 60.5 years), had higher rates of employment (20.9% vs 16.3%), and fewer people living in cities (45.1% vs 27.2%) than the non-Swedish population (see supplementary material, table 2).

Provision of Care

Diagnosing clinician and referral times

Of the 1485 respondents who answered this question, 5% reported that they had been diagnosed by a general practitioner (GP), 34% by a general neurologist, 52% by a specialist neurologist, 4% by a hospital doctor, and 1% by a geriatrician with the remaining 4% stating 'other'. In all of the 11 European countries the majority reported they had been diagnosed by a specialist neurologist, except in France, Germany, and Spain where the majority were diagnosed by a general neurologist ($p < 0.0001$).

If they were referred to another specialist, waiting times varied between <1 month to >4 months to see a general neurologist or specialist PD neurologist, but were generally longer to see a geriatrician, a PDNS or a therapist, with waiting times of >4 months for most healthcare professionals (figure 2 and supplementary material, figure 1). Waiting times to see a specialist PD neurologist were similar between all countries; however there were some differences in waiting times to see a therapist, a PDNS or general neurologist between countries (supplementary material 2).

Medication reviews

74% of the 1328 who responded to this question reported that they had medication reviews by a specialist PD neurologist, 30% by a general neurologist, 23% by a PDNS, 18% by a GP, 9% by a hospital doctor and 5% PwPs had reviews by a geriatrician. Overall, 10% reported their medication is reviewed by any health care professional every 3 months, 37% every six months, 40% once a year and 13% once every two years or more (table 2). In Sweden, medication reviews were more frequent than in the other countries across all health care

professions (all $p < 0.0001$) except by geriatricians. The frequency of review by country is shown in table 3 supplementary materials and by health care professional in table 3.

Satisfaction with care

Satisfaction with care by aspect of care

Almost two thirds of participants reported satisfaction for how involved patients felt in decisions on their treatment ($n = 819/1304$, 63% of respondents who answered this question) and for their family's/carer's level of involvement with decisions about treatment (667/1079, 62%), followed by the way healthcare professionals communicated with PwPs about their condition and treatment options (722/1265, 57%), and information received from healthcare professionals (689/1269, 54%; figure 3). Approximately half (663/1270; 52%) were satisfied with how often their treatment plan was reviewed and with the suitability of their treatment for their condition and circumstances (665/1288; 52%) and 564/1181 (48%) were satisfied with the availability and accessibility of suitable treatment options when they need them. Satisfaction was lowest (462/1114, 41%) for patients' perception of the way the various health care professionals work together to deliver treatment and care. In the sensitivity analysis, in both the Swedish (59%) and non-Swedish sample (67%), satisfaction was highest for how involved patients felt in decisions on their treatment and lowest for the way various health care professionals work together to deliver treatment and care (32% in the Swedish and 49% in the non-Swedish sample).

Level of satisfaction with aspects of care by country is shown in supplementary material, figure 2. All countries were most often satisfied with how involved patients felt in decisions on their treatment, except in Hungary (the way healthcare professionals communicated with PwPs about their condition and treatment options, 84% satisfied), France (how often their treatment plan was reviewed, 78%), Slovenia (information received from healthcare professionals, 65%), Spain (family's/carer's level of involvement with decisions about treatment, 57%), and Italy (availability and accessibility of suitable treatment options when they need them, 33%).

All countries were most often dissatisfied with the way various health care professionals work together to deliver treatment and care, except in Slovenia (45%) where they were most often dissatisfied with how often their treatment plan is reviewed and in Italy (14%) where they were most often dissatisfied with their carer's level of involvement in decisions about treatment.

Satisfaction with care by profession

The highest satisfaction levels with overall care were reported with care received from Physiotherapists (n = 639, 77% of respondents), followed by specialist neurologists (819, 73%) and 534 (73%) from a PD Nurse specialist. 602 (60%) of PwPs reported that they were satisfied with the care they received by their GP, 219 (52%) from their hospital doctor, 372 (57%) from their general neurologist, and 73 (49%) were satisfied with the care they received from their geriatrician (figure 4). In the sensitivity analysis, whilst the Swedish respondents were most satisfied with the care received from specialist neurologists (76% satisfied) and lowest for hospital doctor (44%), the non-Swedish sample reported that they were most satisfied with care received from physiotherapists (80%) and least satisfied with geriatricians (44%).

Satisfaction with care by healthcare profession between countries is shown in supplementary material, figure 3).

Correlates of overall satisfaction with care

There was no significant correlation between overall satisfaction with care and age, and there was no difference between genders, between employed or unemployed participants, and between rural, town and city dwellers in satisfaction with care. There were weak positive correlations between satisfaction with care and disease duration ($r=0.14$, $p<0.0001$) and some aspects of care and level of disability, and between overall satisfaction with care and frequency of medication reviews ($r=0.17$, $p<0.0001$). Overall satisfaction with care was not associated with waiting times to see another specialist. There were positive correlations, with satisfaction with the initial consultation ($r=.26$, $p<0.0001$), with how sensitively patients were told they had PD ($r=.24$, $p<0.0001$) and with the quantity of information provided ($r=.24$, $p<0.0001$). In the sensitivity analysis, similar correlations were reported in the Swedish and non-Swedish respondents.

Discussion

Experiences of care varied considerably between respondents. The majority reported waiting times of less than 4 months if they had been referred to a general neurologist or specialist PD, although a substantial proportion reported having waited longer. The frequency of subsequent, ongoing reviews by specialists was then much less frequent in the majority, typically once or twice a year with a minority seeing a specialist more frequently. 13% were reviewed only every two years or less often. Waiting times to see therapists or PDNS, where available, were often long, reflecting the limited availability of PDNS and lack of resources for allied health care professionals (5). However, this was not associated with reported overall satisfaction with care. Satisfaction with care received by PwP was highest for how

health professionals involve PwP, and their families or carers, in decisions on their treatment, how they communicate with them about their condition and treatments, and with the information they provide. Whilst there is no previous survey to our knowledge that assessed satisfaction with involvement in treatment decisions in PD, in a previous survey by the EPDA in Europe(6) 11.6% of participants reported that they made treatment decisions on their own and 50.6% together with their healthcare professional. It could be argued that those reporting not being involved in these decisions prefer for them to be made by healthcare professionals. However, this contrasts with the finding in this survey that only 63% were satisfied with their involvement in these decisions, highlighting that there is still a continued need to increase patient participation in management decisions in PD. As the survey represents the cumulative experience of PwP over an average of ~8 years disease duration, this may have improved more recently but it is likely that many still perceive lack of sufficient involvement of their own and their carers' views, and lack of information being provided.

Approximately half of all participants reported satisfaction with the frequency of reviews of their medication, with how the treatments given were suited to their personal needs, and with the availability and accessibility of treatments when needed. These opinions on the provision of health care, mirroring the often very infrequent reviews reported by participants and the long referral times to other health care professionals and therapists, highlight the impact of lack of resources to provide regular reviews particularly with advancing disease, access to therapists to respond to an individual's needs on a personalised basis, and prevent deterioration, and a personalised, responsive system to address complications when they occur. It also highlights that only half of PwP feel that a personalised approach, suited to the individual's condition and circumstances as opposed to a standardised approach for PD, is insufficiently provided.

The poorest satisfaction rating was however reported for the way professionals work together to provide care. This is particularly relevant at times when exacerbations occur, and it reflects the lack of joined-up and integrated care across services for PD in many health care systems. This is notable as integrated care with increasing emphasis on multidisciplinary approaches is a key aim for many health care systems, with evidence suggesting better outcomes, greater satisfaction and cost savings (7-11).

The low satisfaction with a personalised, responsive and integrated approach to the care of PwP is also at odds with an increasing emphasis on patient-centered care in modern health care systems. Key components of patient-centered care have been outlined as including greater emphasis on patient and caregiver perspectives and priorities, and efforts to close gaps in knowledge among patients and caregivers in a variety of aspects (12). Whilst there is considerable variability in preferences for decision making and provision of communication (13), studies have outlined that, in addition to addressing their motor and non-motor problems, PwP want their physicians to listen to them and take their concerns seriously, improving two-way communication between patient and physician, to explain their disease comprehensively, and to provide the latest information on PD and its treatment, while also taking into account their anxiety toward the future, communication difficulties, and slowness (14). However, addressing these issues often takes additional time, which can be difficult to provide in a general neurology clinic, or requires additional appointments, e.g. with a PDNS or other health care professional. In more advanced disease, with more complex needs requiring a multidisciplinary approach, the need for greater integration of services was highlighted in a Dutch study in nursing homes, which found that poor access to specialists and coordination of care was one of the unmet needs together with the need for emotional support and improved knowledge of PD(15). Whilst there was only a weak correlation disease duration with overall satisfaction with care, easier and better communication between

health care professionals is particularly relevant with advancing disease when timely intervention for often complex needs is often needed and information needs to be communicated between different health care professionals. We did not collect health economic data, but it is highly likely that the poor communication and integration of care between health care professionals also results in increased costs through hospital admissions and deterioration of symptoms.

There were significant correlations of overall satisfaction with care with frequency of medication review, possibly as a marker of accessibility of care, and with the initial diagnostic experience, including how the diagnosis was communicated; despite the fact that average disease duration was over 8 years. Whilst the causality in a cross sectional survey cannot be established and those overall unhappier with treatment may also have viewed their initial experience more negatively, this emphasises the importance of the initial consultation and the need to communicate the diagnosis sensitively.

Little previous information on these aspects of health care provision is available in PD although there is evidence from other disorders that outcomes can be improved through integrated working(10) with increasing efforts to improve collaborative working(16).

A previous US-based study surveyed members of a US Parkinson's registry(17), showed similar results to this survey in Europe. Whilst many of the questions were not directly comparable, the results on communication and information by health care professionals about PD and medications in this study were overall also relatively high (56% vs approximately 80% in this survey), and there was greater overall satisfaction with PD specialists than general neurologists. In both surveys fewer respondents were satisfied with information on non-drug treatments (28% vs 41%). despite increasing recognition of the importance of these aspects (18).

Limitations

Participants were recruited through volunteers from national organisations and, particularly as we do not have information on non-participants, may therefore be biased towards more active and engaged PwP, and towards those actively seeking greater involvement in their care. Satisfaction with information and involvement may be higher in those who seek less active engagement, but this group may also be more dependent on better communication of health care professionals. Furthermore, nearly half of all respondents on the survey were from Sweden. However, when excluding the Swedish sample from the analysis, the results were overall comparable. Nevertheless, due to the relatively small number of participants in each of the other countries, the retrospective nature of the survey and possible differences in recruitment bias, results of differences between countries should be interpreted cautiously. We had no possibility of verifying the diagnostic accuracy in those who completed the survey. However, it is unlikely that, given the large sample, the results would vary significantly if only those with a confirmed diagnosis were included. In addition, the range of disease duration ranged from very early disease (<1 year) to very long standing disease duration (>40 years) and it is likely that the results of this survey are representative for PwP across disease stages.

Whilst acknowledging the limitations of the nature of this survey, this large survey of the experiences of PwP in Europe suggests that despite the increasing constraints in health care systems, there is a need to adjust health care services for PwP, e.g. by providing more flexible appointments, increasing provision of information in PD and its management to PwP and non-specialist health care professionals, and improving links between healthcare professionals. This has the potential to substantially improve satisfaction with care in PwP, with limited need for additional resources.

Conflict of interest: Dr. Hotham and Dr. Merritt report grants from European Parkinson's Disease Association (EPDA), during the conduct of the study. Dr. Schrag reports funding from the European Parkinson's Disease Association.

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Figure 1.

Waiting times to see different health care professionals from referral

*PD – Parkinson's Disease, PDNS – Parkinson's Disease Nurse Specialist, OT – Occupational therapist, SPAL – Speech and language therapist

Figure 2.

Satisfaction with care by aspects of care

Figure 3.

Satisfaction with care by provider

*GP – General practitioner, PDNS – Parkinson's Disease Nurse Specialist, OT – Occupational therapist, SPAL – Speech and language therapist

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Table 1. Demographic and clinical characteristics of participants

	Mean (SD)
Age of onset	58.5 (10.0)
Male:Female (n (%))	958 (54): 817 (46)
Employed (n (%))	333 (18.8)
Years since diagnosis	8.2 (6.1)
Disability level (Median (Range))	80 (0-100.0)
Country (n (%)):	
UK	110 (6.3)
Holland	175 (10.1)
Denmark	146 (8.4)
France	47 (2.7)
Hungary	66 (3.8)
Germany	84 (4.8)
Spain	64 (3.7)
Slovenia	90 (5.2)
Italy	151 (8.7)
Sweden	806 (46.3)
Habitat (n (%)):	
Rural	343 (19.4)
Town	655 (37.0)
City	774 (43.7)

Table 2. Frequency of medication reviews by clinician (n= 1328*)

	GP (%)	Hospital Doctor	General Neurologist	Specialist PD neurologist	Geriatrician	PD Nurse	Any (%)
Once every 2 years or more	80 (34)	24 (19)	88 (22)	137 (14)	10 (15)	56 (18)	173 (13)
Once a year	63 (27)	43 (35)	162 (40)	412 (42)	21 (31)	112 (36)	526 (40)
Every 6 months	73 (31)	45 (36)	120 (30)	360 (36)	31 (45)	114 (37)	488 (37)
Every 3 months	20 (8)	11 (10)	31 (8)	75 (8)	6 (9)	29 (9)	141 (10)

*excluding missing data

N = 1775





