Nurse specialist interventions in Parkinson's disease

Rosín Ward and **Patrick Browne** evaluate the care of people with Parkinson's disease in the west of Ireland and compare it to corresponding care provided in the UK

PARKINSON'S disease (PD) is a progressive neurologic disease caused by loss of dopamine producing neurons in the substantia nigra of the brain.[1] The resulting depletion in dopamine gives rise to the characteristic motor symptoms of PD: the resting tremor, rigidity, slow movement (bradykinesia) and the mask-like expression (hypomimia).[2] Additionally, there are non-motor features in the disease to contend with. These include sleep disorders, cognitive issues, mood disorders and gastrointestinal issues.[3] Current PD treatment can improve both motor and non-motor symptoms. At the moment, there is no treatment available for PD patients that can slow the neurodegenerative process. This has been described this as 'a major unmet need'.[1]

Parkinson's disease nurse specialists (PDNS) help patients to manage their illness through making changes to their prescription as necessary, monitoring their condition, giving information and support to people with Parkinson's, as well as raising awareness of the condition.[2] This role is integral in providing quality of life for sufferers. Despite this, the positions of PDNS or movement disorders clinical nurse specialist (MDCNS) are poorly funded in the Republic of Ireland, with only five nurse specialists. This paper aims to audit Parkinson's care provided in the west of Ireland by comparing it to practice in the UK through surveys distributed via email.

Methods

This article concerns a retrospective audit of clinical scenarios that attended the west of Ireland MDCNS over a one-month period and is qualitative in nature. Some 219 PDNSs in the UK were contacted via email or telephone and asked if they would like to participate. Eighty-four nurses consented to participate and the survey was distributed to them via email, although there was also the option to complete the survey over the phone.

In the survey, five case scenarios were anonymously depicted and the PDNSs were asked what interventions they would put in place for that patient.

Thirty-five surveys were returned, including the west of Ireland MDCNSs. Some of the reasons for not returning the survey included being away on annual leave and lack of time. The survey was also completed by the west of Ireland MDCNS to provide a means for comparison between west of Ireland practice and practice in the UK.

The returned surveys were analysed and the data were entered into IBM SPSS Statistics (version 20) for statistical analysis. Three of the most common themes from each case vignette were selected and discussed.

As illustrated in *Tables 1-4*, the mean duration in post of the 34 UK PDNSs is 88.62 months with a standard deviation of 51.661 months. The west of Ireland MDCNS has held the post for 107 months. Of the seven services potentially provided by UK PDNSs outlined in *Table 3,* 8.82% provide deep brain stimulation, 11.76% provide clozapine monitoring, 97.06% offer support via telephone, 64.07% participate in clinical research, 94.11% are involved in clinical teaching, 82.35% provide advanced therapy monitoring and 97.05% of UK PDNSs surveyed were nurse prescribers. The west of Ireland MDCNS provides all of these services (*Table 4*). *Table 5* depicts the themed interventions derived from the returned surveys including the west of Ireland MDCNS interventions.

Table 1: UK PDNS duration in post

	N	Min	Max	Mean	Standard deviation
Duration in post (months)	34	10	180	88.62	51.661
Valid (listwise)	34				

Table 2: West of Ireland MDCNS duration in post

UK PDNS mean duration in post (months)	West of Ireland MDCNS duration in post (months)	Deviation (months)
88.62	107	18.38

Discussion

The mean duration in post for the UK PDNSs (See *Table 1*) is 88.62 months. The west of Ireland MDCNS duration in post is 107 months, 18.38 months longer than the mean UK respondent (see *Table 2*). A mere 8.82% of PDNS respondents provide deep brain stimulation (DBS) programming for their patients. Additionally, only 11.76% of respondents provide clozapine monitoring for their patients. The west of Ireland MDCNS provides both of these services in addition to others (see *Table 4*). In the UK the DBS related services are usually provided by a separate CNS who has specialised solely in the surgical management of PD. This is further evidence that an additional MDCNS is needed for the west of Ireland as there is a higher than average caseload and services types being offered than in the UK.

Table 3: Services provided by UK nurse specialists

Deep Brain stimulation programming	Clozapine monitoring	Telephone support	Clinical research	Clinical teaching	Advanced therapy monitoring	Registered nurse prescriber
8.82% (3)	11.76% (4)	97.06% (33)	64.07% (22)	94.11% (32)	82.35% (28)	97.05% (33)

Table 4: Services provided by West of Ireland MDCNS

Deep Brain stimulation programming	Clozapine monitoring	Telephone support	Clinical research	Clinical teaching	Advanced therapy monitoring	Registered nurse prescriber
Yes	Yes	Yes	Yes	Yes	Yes	Yes

Case Scenario 1

In case scenario 1 (see *Table 6*) non-pharmacological management of hypotension, reducing/stopping quetiapine and reducing the dose of levodopa at night were the three most common responses in the survey. Orthostatic hypotension (OH) can be defined as a drop of 20mmHg in systolic blood pressure (SBP) or 10mmHg in diastolic blood pressure (DBP) after three minutes of standing upright.[6] OH may present as dizziness within a few seconds of standing, dull pain at the back of neck and shoulders and dim or tunnel vision.[6,8] The average estimated prevalence of OH in people with PD is thought to be 30%.[5] However, this figure is issued with caution due to the broad differences in estimations in various studies.

OH can be managed conservatively, pharmacologically or a combination of the two. Conservative management involves use of compression stockings, drinking 450ml of cold water in three to four minutes; 30 minutes prior to rising, sleeping with the head elevated; increasing salt consumption; and reviewing the patient's medications and removing any that may be causing or exacerbating the problem. These methods should be the firstline of treatment for OH.[6] For pharmacological management fludrocortisone and midodrine are popular choices. OH may also occur in hypertensive patients. It is important to continue treating the hypertension as patients with uncontrolled hypertension and OH are two and a half times more likely to experience falls.[7] Angiotension converting enzymes should be used to treat the hypertension as this may also alleviate the symptoms of OH as it increases cerebral blood flow.[8]

Quetiapine is an antipsychotic commonly used for PD patients if they experience psychosis. In general, quetiapine is well tolerated; indeed some have reported improvement in dyskinesias while on the drug due to its dopamine antagonism.[9] However, quetiapine can also cause medication-induced sedation. It has been found that a significantly high amount of patients on quetiapine experienced increased sleeping or need for sleep when compared to risperidone particularly in the daytime ($p < 0.001$).[10] Therefore, it is of little surprise that 16 of the 34 UK nurses recommended a reduction in quetiapine or to have it discontinued, and this is in agreement with the west of Ireland MDCNS. Although there is no validated standard, it is reassuring to see that the consensus on treatment is similar if not the same across the surveyed participants.

Case Scenario 2

In case scenario 2 (*Table 6*) the three most common recommendations were increase levodopa, commence clonazepam and assess cognitive status. Levodopa is a first-line treatment for PD patients.[2] As many of the UK nurses recognised that patient 2 had undertreated PD it is logical that an increase in PD medications followed. This is corroborated by the west of Ireland MDCNS and is also in line with present best management strategies, which are globally recognised.[11] Some 17 UK nurses recommended clonazepam to treat the patient's rapid eye movement behaviour disorder (REMBD). REMBD involves the sufferer vigorously and often violently acting out dreams during REM sleep. Bruin et al state that clonazepam should be used as a firstline treatment in REMBD.[12] The final recommendation was assessing the patient's cognitive status. In addition to the patient's increased forgetfulness, 50% of patients suffering from REMBD will develop dementia within 10 years, making the decision to monitor the patient's cognitive status a wise one.[12] Mamikonyan et al recommend the regular use of the Montreal Cognitive Assessment (MoCA) tool as it is more sensitive to the development of mild cognitive impairment than the MMSE.[13] In fact, MoCA identified mild cognitive impairment in one-third of PD patients who previously achieved a score of normal cognition in the MMSE.

Case Scenario 3

Case scenario 3 (see *Table 6*) suggested interventions included no change to the patient's current PD medication, giving levodopa/carbidopa/entacapone (Stalevo) QDS and assessing the patient's mood. The patient had been complaining of fluctuating tiredness and dyskinesias. Levodopa-induced dyskinesias are involuntary movements caused by high levels of levodopa in the blood. As the disease progresses biphasic dyskinesias may also occur. This is when either a rise or fall in levodopa may produce a dyskinesia. As suggested by 10 of our respondents, lowering the dose of levodopa can reduce the dyskinesias.[14] However, the argument for not changing the PD medications is just as valid. Vlaar et al asserted that the treatment goal for PD patients was to maximise 'on' time and tolerate dyskinesias where possible.[15] Furthermore, dyskinesias should be categorised as acceptable (not interfering with activities of daily living or ADLs) or disabling (interfering with ADLs). Patient 3's dyskinesia was classed as mild, indicating that it was an acceptable dyskinesia that does not necessitate an alteration to treatment.[15]

Depression occurs in 45% of PD patients.[16] Additionally, depression is commonly known as a cause of fatigue. It is important to monitor depression in PD as it can impact greatly on a person's quality of life. In case scenario 3, seven respondents thought that the fatigue experienced by patient 3 was linked to her depression and suggested her mood should be assessed. This would allow for her medications to be adjusted accordingly.

Case Scenario 4

The most popular suggestion in case scenario 4 (see *Table 6*) is to commence treating the patient with a dopamine agonist

Table 5: Interventions

	Themed interventions	No of UK comply (n=34)	Irish Compliance Yes/No	Total Irish and UK compliance
Case scenario 1	Conservative management of hypotension	22	Yes	23
	Reduce/stop quetiapine	16	Yes	17
	Reduce levodopa at night	17	No	17
Case scenario 2	Increase levodopa	30	Yes	31
	Commence clonazepam	17	No	17
	Assess cognitive status	19	Yes	21
Case scenario 3	No change to PD meds	13	No	13
	Give lower dose of stalevo given QDS	10	Yes	11
	Assess mood	7	No	7
Case scenario 4	Commence dopamine agonist	20	No	20
	Reduce dose of neupro and omit if necessary	14	No	14
	Commence low dose levodopa with domperidone cover for nausea	12	Yes	12
Case Scenario 5	Increase levodopa	20	Yes	21
	Refer to multidisciplinary team	11	No	11
	Monitor patient closely	10	No	10

(DA). DAs are a common way of treating PD patients. DAs work by exciting neurons in a similar way to dopamine while producing less dyskinesias.[17] Therefore, DAs are an effective firstline treatment in 'young' PD patients as they allow the development of levodopa-induced dyskinesias to be postponed.[2]

Some 14 of the 34 respondents opted to reduce the dose of the transdermal DA, rotigotine patch or discontinue it. Rotigotine benefits by providing continuous dopamine stimulation and convenient administration. It is generally well tolerated. Nevertheless there are still side effects most often skin irritation as experienced by patient 4.[18] Ale et al indicate that in most PD patients who suffered from skin irritation secondary to a transdermal patch it is not necessary to discontinue treatment as the irritation is usually temporary.[19] Despite this, if irritation persists and the patient finds it intolerable, it is advised that the patch be discontinued immediately.

The final recommendation is to prescribe low-dose levodopa with domperidone cover. As patient 4 has a history of experiencing nausea from her PD medications, it is necessary to prescribe domperidone also. Domperidone is useful as an anti-emetic as other anti-sickness medications may aggravate PD symptoms due to their centrally-acting dopamine antagonistic profile.[3] The plan recommended by the majority of UK PDNSs is in accordance with the west of Ireland MDCNS intervention. Again this is reassuring that a common consensus exists among the nurses who work within this specialised area.

Case scenario 4 saw the greatest divergence between the UK and west of Ireland interventions. The reason the west of Ireland MDCNS decided to commence low-dose levodopa with domperidone was a documented history of oral DA intolerance and a skin reaction to a transdermal DA. For this reason and the increasing symptom burden, low-dose levodopa was deemed necessary. This was a limitation in this case scenario as there was additional information that the UK PDNSs would not have been aware of.

Case Scenario 5

In the final case scenario, an increase in levodopa, patient monitoring and multidisciplinary team involvement are advised. Multidisciplinary team interventions have been shown to improve PD patients' UPDRS motor score, gait speed, speech and quality of life.[20] Although there is little evidence to support the role of occupational therapy, the NICE guidelines advocate its inclusion in PD care.[21]

The numerous symptoms of PD mean that correct case management is necessary to maximise quality of life. This is where a PDNS becomes essential. This is confirmed by a study conducted by the charity Parkinson's UK. It was discovered that twice as many patients found their PDNS more helpful in understanding their local Parkinson's services than a neurologist.[22] As well as providing information on services and advice, the PDNS assesses patients in clinic, can make alterations to medications if they are a nurse prescriber, conducts research and educates other healthcare workers on the condition.[2]

Limitations

This study is limited by the small case scenario sample size, the topic subjectivity and the comparison of different health service models. Additionally, respondents were unable to assess the patient in person, although every effort was made to be transparent with the information the UK PDNSs had to rely solely on the case scenarios they were given.

Conclusion

We sought to compare west of Ireland MDCNS interventions to that of UK PDNSs. Three main themes were selected from

each case scenario response covering a broad amount of topics, including the non-pharmacological management of hypotension, increasing levodopa, not changing PD medication, commencing a DA and referring PD patients to a multidisciplinary team. It was found that the west of Ireland MDCNS was in accordance with the majority of UK PDNS decisions. Additionally, the MDCNS in the west of Ireland is delivering services in accordance with international peers and in excess.

When compared to some UKPDNSs, the west of Ireland service is understaffed, as the numbers of patients per nurse are higher, but the MDCNS also caters for more patient groups than solely those with PD. The National Collaborating Centre for Chronic Conditions (2006) guidelines state that there should be one PDNS for every 300 patients. According to Parkinson's Association of Ireland there are more than 8,000 people with PD in this country. As there are only five PDCNSs (including the MDCNS in the west of Ireland) working for the HSE (at the time of this study in 2013) that results in a ratio of over 1,600 patients to each nurse – greater than five times the recommended level. This demonstrates the need for more MDCNSs in the Republic of Ireland.

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Table 6: Case scenario patient details

Case scenario 1: 71-year-old, right handed male.
PD x 15 years. History of depression, lumbar stenosis, retinal vein occlusion, hypertension and orthostatic hypotension.
Diagnosis: Idiopathic Parkinson's disease x 15 years.
C/O: Increased Daytime Sleepiness and mané dizziness.
Drugs tried and discontinued in relation to PD: Selegilene, Sinemet Plus, Kemadrin 5mg, Rotigotine patch 5mg, Lexapro, Tritace, diovan, Rivastigmine, Domperidone, Azilect 1mg.
Allergies: NKDA.
Investigations: Nil.

Case scenario 2: 67-year-old, right-handed male.
DVT in 2011.
Diagnosis: Idiopathic Parkinson's disease x one and a half years.
C/O: Increased tremor in past few months.
Drugs tried and discontinued in relation to PD: Nil.
Allergies: NKDA.
Investigations: Nil.

Case scenario 3:
76-year-old female. Parkinson's disease x seven years. History of osteoarthritis, infectious hepatitis 1977, Appendectomy 1977, Oophorectomy 1985, R THR in 2010, multinodular goitre 2011, vertigo x six weeks 2006, hypercholesterolaemia, anxiety, lower back pain.
Diagnosis: Idiopathic Parkinson's disease x seven years
C/O: Fluctuating tiredness.
Drugs tried and discontinued in relation to Parkinson's Disease: Sinemet plus, TDS.
Allergies: ? Penicillin.
Investigations: Nil.

Case scenario 4:
56-year-old, right-handed female. History of right breast cancer with lumpectomy in 2008. Irritable bowel syndrome. Osteoporosis 2010.
Diagnosis: Early idiopathic Parkinson's disease x 14 months.
C/O: Skin reaction to neupro patch.
Drugs Tried and discontinued in relation to PD: Requip modutab.
Allergies: NKDA.
Investigations: DAT scan - positive.

Case scenario 5:
67-year-old, right-handed female. Type 2 diabetes 2007 and hypertension (both are well controlled), Bells Palsy 2005.
Diagnosis: ? Corticobasal degeneration or Parkinsonism.
C/O: Decreased function in left hand x two years.

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