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Hospitalization in Parkinson's disease: A survey of UK neurologists, geriatricians and Parkinson's disease nurse specialists

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ABSTRACT

Introduction: Care for people with Parkinson's admitted to hospital is often suboptimal and services for these patients vary. We conducted a national survey to document current service provision in the UK and to explore clinicians' views on standards of care and potential service improvements.
Method: We used the mailing lists of British Geriatric Society Movement Disorder Section (BGS-MDS), British and Irish Neurologists' Movement Disorders Group (BRING-MD), and Parkinson's Disease Nurse Specialists Association (PDNSA) and invited participation by email with a link to an online survey (www.surveymonkey.com). The survey was posted in spring 2014 for six weeks.
Results: There were 93 respondents from at least 65 different hospitals. The estimated response rate was 19%. Respondents were: 35 consultant geriatricians; 21 consultant neurologists, 29 Parkinson's Disease Nurse Specialists (PDNS), 8 others. 81% respondents report their hospital has a PDNS. 79% have a geriatrician with an interest in Parkinson's. 54% have a Parkinson's clinical guideline, 16% a cohort/specialist ward for Parkinson's and 11% an electronic system for flagging Parkinson's admissions. 21% rated overall standard of care as poor. 61% were not confident that medications were given on time. Having a PDNS see all Parkinson's in-patients, flagging of Parkinson's admissions and having a Parkinson's outreach service were ranked most likely of 16 potential service developments to improve care.
Conclusion: Care for Parkinson's in-patients is not highly rated by UK Parkinson's clinicians. Interventions to improve care need to be studied but wide variations in current service provision pose a challenge for future study design.

1. Introduction

Parkinson's disease (PD) is estimated to affect 200 per 100,000 of the population in the UK [1]. It is the second most common cause of chronic neurological disability and the number of people with Parkinson's disease over the age of 50 is expected to double over the next 25 years [2]. People with Parkinson's are 1.45 times more likely than their peers to be admitted to hospital and stay 2–14 days longer [3–5]. People with Parkinson's are more likely to be admitted with an acute medical problem than for Parkinson's itself [6]. Most admissions are emergency admissions and in the UK these have increased by 19% between 2004–5 and 2009–10 [7].

Omission of dopaminergic medication is associated with worse motor performance both in hospital and in the community [8–10]. However, omission of dopaminergic medication, delays in administration of dopaminergic medication and inappropriate use of anti-dopaminergic medication commonly occur when Parkinson's patients are hospitalized [11–16]. Lack of staff with neurological expertise is thought to contribute to poor outcomes for these patients [17]. In a Parkinson's UK survey, of those patients not self-medicating, nearly two-thirds did not get their medication on time every time and one in four felt that not getting their medication on time prolonged their stay in hospital [18].

Both patient and hospital factors may contribute to the difficulties in administering dopaminergic medication correctly. Parkinson's patients are admitted 6× more commonly than their peers

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with aspiration pneumonia so concerns about safe swallowing are frequent [4]. Likewise psychosis and delirium are common and may lead to difficulties with medication. Meanwhile hospital staff may lack knowledge about the importance of giving dopaminergic medication on time. Also hospital in-patient wards may be under stress, under-resourced and under-staffed.

We wanted to understand the state of current service provision in the UK for Parkinson's in-patients. We also wanted to explore the views of UK Parkinson's specialists on the most effective interventions to improve hospital care for people with Parkinson's.

2. Methods

We developed a questionnaire based on known service deficiencies and on public and patient involvement meetings in Derby and Newcastle, UK. We developed and refined a list of 16 interventions or service developments that might improve the quality of care for in-patients with Parkinson's. We asked the specialists to rank these suggested service developments in order of likely efficacy. We also asked some open ended questions about enablers for, and barriers to, improvements in care. Ethical permission was not sought as this was a survey of professionals.

We placed the questionnaire online using Survey Monkey (www.surveymonkey.com). UK geriatricians and neurologists with an interest in PD, and PD nurse specialists (PDNS) were invited to take part. We used the mailing lists of the following organizations and invited participation by email with a link to the online survey: British Geriatric Society Movement Disorder Section BGS-MDS; British and Irish Neurologists' Movement Disorders Group (BRING-MD); Parkinson's Disease Nurse Specialists Association (PDNSA). The survey is included as an online supplement (Appendix 1). The survey was posted for 6 weeks. We asked community-based PD nurses to answer with regard to the main acute hospital in their locality.

The size of the mailing lists of the special interest groups were approximately: BGS-MDS, 100; BRING-MD, 219 and PDNSA 170. It is possible that some individuals were on more than one mailing list.

The frequency and % were used to report the survey results. Median scores were calculated for each intervention to determine which interventions the clinicians thought would be most likely to lead to improvements in care for Parkinson's in-patients.

3. Results

The survey was completed by 93 respondents. The estimated individual response rate was 93/489 (19%). We received responses from at least 65 institutions in the UK which, we estimate, represents about a third of all UK acute care hospitals. Six respondents did not identify the institution they described in the survey. For 10 institutions we received more than one response.

The respondents were: 35 consultant geriatricians; 21 consultant neurologists, 29 PDNS, 4 trainee geriatricians and 4 neurology nurse specialists/advanced nurse practitioners. The sizes of the hospitals represented in the survey were: more than 1000 beds, 16 (23%); 751–1000 beds, 11 (16%); 501–750 beds, 27 (39%); 250–500 beds, 8 (11%); less than 250 beds, 8 (11%); not known 8 (11%).

Responses about current service provision are summarized in Table 1.

Although 76 (81%) respondents report their hospital has a PDNS, 8 (10%) of these do not see hospital in-patients, while 40 (53%) see Parkinson's in-patients on request and 27 (36%) proactively seek out Parkinson's in-patients.

A liaison or outreach service for Parkinson's in-patients was reported by 39 (42%) respondents. Usually this was a 5-day service (39%) and occasionally (3%) a 7-day service. Some other form of referral or advice service was described by 15 (16%) and 38 (41%) had no liaison service at all.

An electronic system for flagging Parkinson's in-patients so that the Parkinson's team can easily identify if their patients are admitted was reported by 10 (11%) respondents. A further 17 (18%) said wards generally let the PD team know about admissions, 7 (8%) said families and carers generally let them know, 16 (17%) described other systems, such as tracking prescription of dopaminergic therapy, to allow the PD service to identify admissions and 42 (46%) reported having no system for identifying these patients.

Table 1
Responses about current service provision for Parkinson's in-patients.

Service specification	Provided (%)
Hospital has Parkinson's nurse specialist (n = 93)	76 (81%)
Parkinson's nurse actively seeks out Parkinson's in-patients (n = 76)	27 (36%)
Geriatrician with a special interest in Parkinson's (n = 92)	73 (79%)
In-patient Parkinson's medication audit (n = 93)	52 (56%)
Clinical guideline for care of Parkinson's in-patients (n = 93)	50 (54%)
Parkinson's outreach or liaison service (n = 92)	39 (42%)
Electronic prescribing (n = 91)	26 (29%)
Neurology ward (n = 93)	26 (28%)
Cohort ward/specialist ward (n = 93)	15 (16%)
Electronic system for identifying/flagging PD in-patients (n = 92)	10 (11%)
Pre-operative optimization service (POPS) (n = 93)	9 (10%)

A specialist Parkinson's ward or cohort ward for Parkinson's in-patients was reported by 15 (16%) respondents. All hospitals with cohort or specialist wards have a PDNS and a geriatrician with a special interest in Parkinson's and 80% have a guideline for the management of Parkinson's in-patients. Most [9/14, (64%)] units with a cohort/specialist ward also had an outreach service. 8 (53%) respondents reporting cohort wards were from hospitals with more 750 beds.

Provision of a formal pre-operative assessment and optimization service (POPS) was infrequent: 3/93 (3%) had a Parkinson's specific POPS service and 6/93 (6%) had a generic POPS service that could see Parkinson's patients. 32/93 (42%) report that the PD nurse or consultant generally write to the surgical team with advice if they know of planned surgery. 9/93 (10%) report some other arrangements such as pre-op assessment services tending to refer to the PD nurse pre-operatively. 43/93 (46%) report no advice service for planned surgery in PD patients.

Audit of in-patient prescription and/or administration of Parkinson's medication was reported by 52 (56%) respondents and in many cases (44/52) this had been within the last 3 years.

Neurology wards were reported by 26 (28%) respondents. 5/26 (19%) of these respondents also reported a cohort ward while 10/67 (15%) respondents without neurology wards report a cohort ward [Fisher's Exact test $p = 0.754$].

The 93 respondents were asked to rate the overall standard of care for Parkinson's patients admitted to their hospital, and to rate staff knowledge of Parkinson's medications. The results are shown in Fig. 1. The opinions of the three different professional groups about overall standard of care are compared in Fig. 2.

56/92 (61%) of respondents were not confident that Parkinson's medication was given on time in their institutions, 32 (35%) were somewhat confident and 4 (4%) were very confident. Concerning doctors' and nurses' knowledge of common anti-dopaminergic medications: 38 (41%) were not confident that staff knew that haloperidol and metoclopramide should not be given to PD patients; 45 (48%) were somewhat confident and 10 (11%) were very confident.

The median rank for each of the potential interventions was determined and the 16 interventions ranked accordingly. See Table 2.

Open ended responses about barriers to, and enablers for, an improved service were provided by 80 respondents and were wide ranging. Inadequate training, knowledge or awareness were cited as barriers to improved care by 40 (50%) respondents. Poor nurse staffing levels on the wards, financial difficulties and wards being too busy were mentioned as a barrier to service improvement by 39 (49%). Poor drug availability was cited by 9 (11%). A full description of the open ended responses about barriers to improved care is included as an online appendix (Appendix 2).