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Workloads of Parkinson’s specialist nurses:

implications for implementing national service guidelines in England.

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ABSTRACT

Aim: To investigate the nature and extent of current roles and responsibilities of Parkinson's Disease Nurse Specialists in the UK National Health Service and explore capacity for expansion in the context of recent service delivery recommendations.

Background: The National Service Framework for people with long term (neurological) conditions promotes additional community support from specialist nurses to maintain patient wellbeing and prevent costly hospitalisations. The National Institute for Health and Clinical Excellence guidelines for Parkinson's disease prescribe an extended role for Parkinson's Disease Nurse Specialists in review and management of patients. With the patient base rising, concerns exist about the ability of available resources to meet enhanced requirements.

Design: A national mailed survey of Parkinson's Disease Nurse Specialists in England and Wales, 2006.

Methods: A questionnaire was designed, piloted and distributed to all Parkinson's Disease Nurse Specialists and nurses with a special interest in Parkinson's on the database of the Parkinson's Disease Society. Items covered workloads and service delivery.

Results: Eighty nine nurses responded. They reported high case loads (mean 526 patients, range 20 – 1800) and undertaking a broad range of patient – centred tasks (medications advice and prescribing, support, education, symptom management, care co-ordination, assessment, care planning). The most frequently mentioned barrier to service delivery was lack of time, cited by 31 (34.8%). Over 70% of respondents favoured having some assistance, but views varied about the most appropriate type.

Conclusion: Most Parkinson’s Disease Nurse Specialists have caseloads well in excess of National Institute for Health and Clinical Excellence recommendations and many express concerns about the effect of workload pressures on quality of care.

Relevance to clinical practice: More resources are required to meet the level and quality of service set out in national guidelines. Deployment of trained assistants to work with Parkinson’s Disease Nurse Specialists might facilitate implementation of service guidelines and is consistent with UK National Health Service workforce policy. More research is required on optimal case loads and models of service delivery.

Keywords

Parkinson’s disease, Specialist nurse, Caseload, Assistant, Questionnaire, nursing

INTRODUCTION

The British National Health Service (NHS) guidelines for managing people with long term (neurological) conditions are for additional community support and increased access to maintain wellbeing and prevent costly hospitalisations (Dept of Health 2005). This National Service Framework (NSF) identifies three levels of care ranging from supported self management at the base of the pyramid to intensive professional input coordinated by case managers (sometimes called community matrons) for people with multiple complex needs at the apex (Dept of Health 2005). Between these layers lie disease–specific specialist nurses who work in community or acute settings to deliver and coordinate multidisciplinary care for their patient groups. In the UK, people with Parkinson's were amongst the first have access to a specialist nurse and there are now only a few areas without cover.

Consistent with the NSF, the National Institute for Health and Clinical Excellence (NICE) guidelines for the management of people with Parkinson's disease prescribe an extended role for specialist nurses (NICE 2006). With the patient base rising, concerns exist about the ability of available resources to meet these enhanced requirements. We undertook a national survey of Parkinson's Disease Nurse Specialists (PDNS) in summer 2006. The aim was to investigate the nature and extent of the current roles and responsibilities of PDNS and to explore the capacity for expansion in the context of recent service delivery recommendations.

BACKGROUND

Specialist nurse roles have been developed in many countries and across a wide range of conditions, including diabetes, Chronic Obstructive Pulmonary Disease (COPD), heart disease and mental health (Lloyd Jones 2005). Early studies of the evolving role of nurse specialists showed that they deliver responsive, patient-centred care that is highly rated by their clients (Wilson-Barnett and Beech 1994). Over time their responsibilities have extended and they now perform a variety of tasks including case management and the provision of education, advice and support to patients, family carers and other health professionals (Candy *et al* 2007).

Parkinson's specialist nurses in the UK undergo training to assume their role and many gain prescribing qualifications. They usually work in multidisciplinary teams (MDT), with general and specialist doctors and a range of therapists, to deliver care to patients at all stages of the disease. Many nurses run their own clinics, make home visits, refer to other experts and coordinate care packages according to patient needs (Noble 1998). Parkinson's nurses are often the first point of contact for patients ensuring fast access to specialist care, whilst relieving pressure on neurologists who are in short supply. The PDNS role has been evaluated in hospital and community settings. Compared to consultants, PDNS have been shown to give longer consultations and to pay more attention to patients' concerns (Reynolds *et al* 2000). People with Parkinson's managed in the community by a nurse specialist were found to have improved subjective wellbeing at no extra cost, compared to those in the GP group (Jarman *et al* 2002).

If the widened remit of PDNS envisaged by the NSF for long term (neurological) conditions and NICE guidelines for Parkinson’s disease are not accompanied by a commensurate increase in community resources, the access benefits and patient – centred approach to care are threatened. The national survey of PDNS was designed to explore working conditions and views on this issue.

METHODS

The local NHS committee confirmed that an ethical opinion on the study was not required, but approval was gained from the University of Surrey. The survey instrument was designed in consultation with several PDNS and piloted. The Parkinson’s Disease Society (PDS) holds a national database of PDNS and nurses with a special interest in Parkinson’s. For data protection reasons, the research team was not able to have direct access to the database and the PDS mailed the questionnaire, cover letter and freepost envelope for return of completed forms to all the names on it. A second mailing was organised after four weeks, asking nurses who had not responded to the first circulation to participate. An article was also placed in the PDNS Association journal to draw the attention of members to the study.

The questionnaire contained 19 items, in three sections, covering PDNS job details (location, caseload, activities), perceptions of service delivery (barriers, facilitators, gaps and areas of excellence) and views about having assistance (pros and cons, tasks that could be delegated and training needs). It could mostly be completed by tick boxes, but there were also some open comment fields where the opinions of PDNS were sought. The data were entered into Access and SPSS data bases for descriptive analysis. Text responses were entered into NVivo to identify themes.

RESULTS

Eighty nine responses were received. Most respondents (n=54, 60.7%) were nurses who had specialised in Parkinson's for more than five years. Seventy-two (80.9%) respondents had completed PDNS training and a further eight (9.0%) were undergoing training. The remaining nine respondents were nurses with a special interest in Parkinson's. Just over three quarters of respondents (n=68, 76.4%) worked exclusively with people with Parkinson's and one third (n=29, 32.6%) were qualified to prescribe.

Respondents reported high case loads (mean 526 people with Parkinson's, median 490, range 20 – 1800) and undertaking a broad range of patient – centred tasks (including, in order of frequency of responses, medications advice and prescribing, support, education, symptom management, care co-ordination, assessment and care planning), by means of clinic appointments, home visits or telephone (Table 1). Virtually all PDNS were well networked and received referrals from a variety of sources and provided access for patients to a range of services. Most (n=84, 94.4%) also made home visits and PDNS from rural areas reported travelling up to 1200 miles per month in this respect (mean 362, median 310 miles).

Barriers, facilitators, gaps and areas of excellence in service delivery identified by the respondents are shown in Table 2 and 3. There is evidence that access to MDT and other services is patchy. Some respondents highlight liaison amongst MDT members as a facilitator of service delivery (n= 50, 56.2%) and an area of excellence (n=41, 46.1%), whilst others note problems with communication as a barrier (n=12, 11.2%) and a lack of allied health professional support as a gap (n=20, 15.9%). Consistent with the reported high caseloads, the most frequently identified barrier to service delivery was lack of time, mentioned by 31 (34.8%) of respondents. Absence of clerical assistance was specifically raised by 25 (28.1%) of PDNS. ‘Having a helper’ was recognised to be a significant facilitator by respondents who already had them (n=21, 23.6%). In most of these cases (n=15, 71.4%), the helper was a local PDS volunteer. In the remaining instances, the help was in the form of dedicated secretarial support (for filing, putting information on the computer, typing letters, completing referral forms), or other PDNS.

Responses from PDNS were more than two to one in favour of having a trained assistant to work with them on care delivery (n=64, 71.9% vs n= 23, 25.8%, n=2 did not respond). Reasons in favour were predominantly (over 90%) to assist with the ‘enormous’ workload and as a means to extend and improve the quality of the service they could offer. Respondents mentioned a desire to spend more time on difficult cases whilst an assistant could engage in more routine follow up and non medication - related issues, such as providing general advice and support and clerical duties.

DISCUSSION

The responses to this national survey confirm that PDNS have patient – focused remits and that they are performing care planning, monitoring, management and co-ordination functions as identified in current national guidelines. However, many PDNS in Britain report high caseloads and express concerns about the effect of workload pressures on quality of care and their ability to provide all people with Parkinson's with the expected level of service. With most respondents working at or above capacity, available resources may not be adequate to shift care from hospitals to the community to the extent envisaged in recent policy. Whilst NICE recommends a caseload of 300 (NICE 2006), half of the PDNS respondents report having 500 or more patients on their lists. High caseloads may reduce service delivery costs in the short term, but they also affect quality of care (Zeliff Massie 1996) and may increase service utilisation in the long run. Recent evidence from a qualitative study of community matrons found that excessive caseloads adversely affected morale, created a need to risk stratify patients and resulted in a shift from proactive to reactive care (Sargent *et al* 2008). Parkinson's specialist nurses in the survey similarly identified that 'crisis management' displaces other roles emphasised by current guidelines, particularly routine support and the maintenance of wellbeing through regular review.

We have no way of establishing the exact response rate to the survey, or the existence (if any) of non response bias. We understand that 220 questionnaires were mailed to PDNS and nurses with a special interest in Parkinson's on the PDS database. However, this database had accumulated over a decade, had not been recently updated and contained an unknown number of people who had retired, moved to other professions or were taking a career break. With 89 questionnaires returned, the minimum response rate to the survey is 40.3%, but we believe the proportion of active PDNS or nurses with special interest in Parkinson's who participated to be considerably higher than this.

One way work pressures of PDNS might be relieved could be to deploy trained care assistants to work with them. Some 20% of respondents already have help of some kind and acknowledged its value. Overall 70% of PDNS thought the idea of trained assistants was a good one. Views varied about the best form that assistance should take. Some wanted another specialist nurse, others favoured a volunteer PDS community support worker or clerical help, rather than a nursing or health care assistant. Legitimate concerns were raised about provision of appropriate training for assistants, role definition and boundaries of responsibilities, accountability and protecting the role of specialist nurses in an environment of resource constraints and budget cuts.

The training of unregistered workers is part of NHS strategy to break down traditional demarcations between professions and occupations and make the healthcare workforce more flexible and responsive to the needs of patients. Enhanced roles for support workers (also known as health care assistants, nursing auxiliaries, nurse assistants and by various other titles) at the interface of health and social care are supported by the Royal College of Nursing (RCN 2003; RCN 2006) and viewed as a means by which advanced practice nurses can be freed from routine tasks to concentrate on more highly skilled aspects of their job, thereby improving the efficiency and effectiveness of service delivery (Adams *et al* 2000). Many new roles are emerging in the NHS, including rehabilitation and mental health assistants.

Means to address issues of competency, accountability, patient safety and quality of care are being developed (Hyde *et al* 2005; Spilsbury and Meyer 2005; McKenna *et al* 2004) and formal mechanisms are in place to promote role redesigns, including the Changing Workforce Programme, the Agenda for Change (a national job evaluation and pay scheme) and the Knowledge and Skills Framework (to define competencies and training needs for job profiles throughout the NHS). In this environment, the development of a Parkinson's care assistant role, in community MDT, could complement the work of PDNS and other health care professionals.

CONCLUSION

Specialist nurses provide high quality disease-specific care to patients but PDNS are concerned about maintaining standards of care. More front line resources are required to meet the level and quality of service delivery set out in the national guidelines. In the short term, more help needs to be provided to PDNS in ways they would individually find most beneficial. In the longer term, evidence is required about the cost-effectiveness of different models of care (NICE 2006) and what aspects of PDNS work provides greatest benefit. Determining appropriate productivity levels for community nurses is an important concern for commissioners of care (Rice 1997) and a need has been identified for further research into suitable caseloads for advanced practice nurses in the community (Wilson and Cooper 2008; Sargent *et al* 2008), optimal skill mixes (Richardson *et al* 1998; Sibbald *et al* 2004) and the cost-effectiveness of teams involving assistants compared to nurse-only approaches (Huston 1996). By virtue of their role, many nurse specialists are easily accessed by patients and in high demand, so our findings for PDNS may be generalisable in other specialty areas, but further research is needed to confirm this, including in other health care systems where the organisation and structures of care are different from those of the British NHS.

RELEVANCE TO CLINICAL PRACTICE

Parkinson's Disease Nurse Specialists working in the British NHS fulfil a broad range of patient – centred tasks including medications advice and prescribing, support, education, symptom management, care co-ordination, assessment and care planning. However, over 80% of respondents to a national survey report case loads in excess of current recommendations, inadequate time to me*et al*l patient needs and concern about their ability to continue to deliver high quality care. More resources are required to meet the level and quality of service set out in national guidelines. Deployment of trained assistants to work with PDNS might facilitate implementation of service guidelines in a cost- effective way and is consistent with NHS workforce policy.

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Table 1: Self reported case loads and roles of PDNS respondents (n=89)

Aspect of role	**Number replying to question**	**Categories of response**	**n**	**%**
What is your Parkinson's case load?	84#	Less than 100	2	2.4
		100 – 199	7	8.3
		200 - 299	8	9.5
		300 – 399	20	23.8
Mean: 526		400 - 499	7	8.3
Median: 490		500 - 999	34	40.5
Range: 20 -1800		1000 – 1499	3	3.6
		1500 or more	3	3.6
Who refers people with Parkinson's to you?	89	Consultant	85	95.5
		MDT members	83	93.3
		GP	82	92.1
(Tick as many as apply)		Social services	69	77.5
		Open / self	62	70.0
		PDS CSW	51	57.3
		Other*	19	21.4
Who do you refer people with Parkinson's to?	89	Occupational therapist	88	98.9
		Physiotherapist	88	98.9
		Speech & language therapist	88	98.9
(Tick as many as apply)		Social services	85	95.5
		Day hospital	69	77.4
		PDS CSW	60	67.4

		Other**	55	61.8
What are the main areas of your work? (Open question analysed using NVivo)	76 (stating 253 items)	Medicines advice,prescribing	42	16.6
		Support, counselling, advice	40	15.8
		Education and information	37	14.6
		Disease / symptom / care management	29	11.5
		Clinic	25	9.9
		Liaise MDT, coordinate care	24	9.5
		Assessment, care planning	18	7.1
		Home visits	12	4.7
		Telephone advice	10	3.9
		Total care (diagnosis to death)/ as the PDS job description/ huge remit.	9	3.6
		Research	3	1.2
		Administration	2	0.8
		TOTAL	**253**	**100**

MDT: Multidisciplinary team

CSW: Community Social Worker

Responses showed evidence of ‘rounding’, Eg in the 500 – 999 category, 9 PDNS stated 500.

* Pharmacist, hospital, district nurse, mental health, continence service

** 101 different services were mentioned, including: psychiatric/ psychology (11); voluntary organisations eg Age Concern (10), dietician (9); continence (7); community nurse (7); day centre (6); chiropody / podiatry (5); palliative (5); dentist (3); respite (2).

Table 2: Barriers and facilitators to service delivery to people with Parkinson’s (n=89)

Barriers: 6 respondents stated –none. The remaining 83 respondents gave a total of 155 barriers			**Facilitators:** 82 respondents gave a total of 126 facilitators		
Barrier	**N**	**%**	**Facilitator**	**N**	**%**
Lack of time	31	20.0	Close liaison and support MDT, GPs	50	39.7
Lack of clerical /admin help	25	16.3	Having a helper	21	16.7
Caseload too high	23	14.8	Telephone advice	9	7.1
Large area / distance travelled	18	11.6	Run clinics	7	5.6
Inadequate Parkinson’s facilities/ MDT access	15	9.7	Access to a neurologist	7	5.6
Resource cuts and constraints	13	8.4	Being autonomous	7	5.6
Poor liaison primary, secondary care and MDT	12	7.4	Having good manager	6	4.8
Poor liaison between PDNS and GP	8	5.2	Home visits	5	4.0
Inadequate day / respite services	5	3.2	PDNS network	5	4.0

NHS policy / job changes	3	1.9	Own motivation, organisation	5	4.0
‘I lack knowledge’	2	1.3	Being able to prescribe	2	1.6
			PDS information sheets	2	1.6
TOTAL	**155**	**100**	**TOTAL**	**126**	**100**

Table 3: Gaps and areas of excellence in service delivery (n=89)

Gaps: 77 respondents gave a total of 87 gaps			**Areas of excellence:** 73 respondents gave a total of 87 areas of excellence		
Gaps	**N**	**%**	**Areas of excellence**	**N**	**%**
Not enough nurses / no time / can’t cover all and do follow up or education	25	28.7	Local Parkinson’s programmes / MDT access	41	47.1
			Telephone advice service	8	9.2
MDT / allied health professional / rehabilitation services lacking	20	23.0	Open access (patient /carer self referral)	6	6.9
			Continuity of care	6	6.9
Psychology, psychiatry services lacking	12	13.8	Special Parkinson’s clinics	6	6.9
Can’t do home visits out of area	5	5.7	PDS local liaison	5	5.8
No home visiting	4	4.6	Fast response	5	5.8
No specialist neurologist	4	4.6	Specialist Parkinson neurologist	5	5.8
Services for young onset lacking	3	3.4	High patient satisfaction	3	3.4

GPs don’t refer Hard to reach ethnic minorities	1 1	1.2 1.2	Botox service (for drooling) Access to surgery	1 1	1.2 1.2
TOTAL	**87**	**100**	**TOTAL**	**87**	**100**