Discussion Paper Briefing Report Consensus

Neurology specialist nurses and Multiple Sclerosis

October 2014

Introduction and objectives

Specialist nurses play an invaluable role in supporting people with MS with expert information, support, assessment, treatment and co-ordination of care, throughout the course of their condition[1]. There are currently around 245 condition-specific MS specialist nurses (MSSNs) across the UK[2], along with around 325 condition-specific nurses for Parkinsons Disease[3], 180 for Epilepsy[4] and a further number specifically for Motor Neurone Disease (MND) and some other neurological conditions.

Alongside condition-specific nurses, there are a number of Neurology Specialist Nurses (NSNs) who work across more than one neurological condition. In 2014, as part of a wider project, the MS Trust set out to establish:

- how many NSNs there are in the UK and where they work;
- which conditions they work with;
- how they divide their time;
- their perspectives on the benefits and challenges of working across multiple conditions.

The overall objectives of this discussion paper are:

1. to improve understanding about the key nursing roles delivering expert care to people with MS
2. to contribute to the collective knowledge of neurological patient organisations with a particular interest in specialist nursing provision
3. to provide useful insights to commissioners and managers about models of nursing provision
4. to stimulate discussion about whether Neurology Specialist Nurses or condition-specific nurses are best placed to meet the needs of people with MS and other neurological conditions.

1. Mynors et al, Defining the Value of MS Specialist Nurses, MS Trust 2011
2. MS Specialist Nursing in the UK – 2014, MS Trust 2014
3. Parkinsons UK data, 2014
4. Epilepsy Action data based on membership of the Epilepsy Specialist Nurses Association, October 2014

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32 neurology specialist nurses were identified across the UK.

Methodology

We sought to identify as many NSNs as possible, in the following ways:

- Using the MS Trust professional database, through which we have existing contacts with a number of NSNs through participation in our professional development programme
- By asking other organisations with whom we work: Parkinsons UK, Epilepsy Action, the Epilepsy Society and the MND Association
- By asking all MS Specialist Nurses (MSSNs) about any NSNs they were aware of working in their area. This was done as part of a national survey of MSSNs conducted in mid 2014 which achieved a response rate of over 95%.

Through these methods (and after removing duplicate suggestions), 28 NSNs working with MS and other conditions were initially identified[5]. Whilst we cannot be entirely confident that we have identified all the NSNs in the UK, we are not aware of any geographic gaps in our data collection[6]. However, there may be a small number of cross-condition NSNs who do not cover MS within their remit, and we suggest that further efforts should be made to identify these.

We sought information from the NSNs in three ways:

- An online survey, sent out in March 2014, asking for information about their hours of work, setting of practice and conditions covered.
- A supplementary online survey, sent out in August 2014, asking for a more detailed breakdown of time spent on different conditions and about the commissioners / Health Boards served by their service.
- Semi-structured telephone interviews held with six NSNs (four interviewed individually, two together) asking about caseloads and exploring their perspectives on the benefits and challenges of the NSN role.

Between the first and the supplementary survey, two nurses left their posts and six additional nurses were identified, resulting in a final sample of 32 nurses. As a result, not all questions were answered by all nurses, and the data presented below has been adjusted accordingly.

Findings

Number, whole time equivalents and location of posts

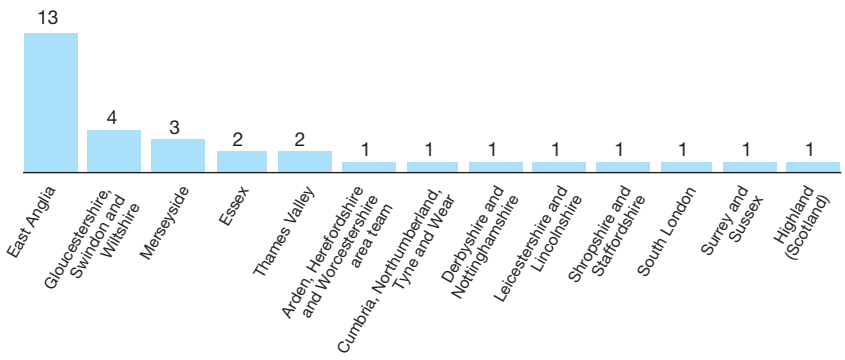
63% of NSNs reported that they were employed full time (a similar proportion to MSSNs) and, of the nurses working part time, the average amount of time employed was 0.65 whole time equivalent (WTE). The 32 NSNs (headcount) represent approximately 29 WTE posts.

Looking at the geographical location of the posts, notably over a third are based in East Anglia (12 in Norfolk and one in Suffolk), with a further three working from the Walton Centre on Merseyside. Only one NSN post was identified in Scotland and none in Wales or Northern Ireland.

5. This number aligns well with 25 NSNs that Parkinsons UK have identified working with Parkinsons and other conditions.
6. There are four NSNs working in the Channel Islands: Jersey and Guernsey, who are outside the UK NHS and therefore excluded from our analysis.

21 out of 32 NSNs cover 4 or more neurological conditions.

Number of NSNs identified by NHS Area Team/Health Board

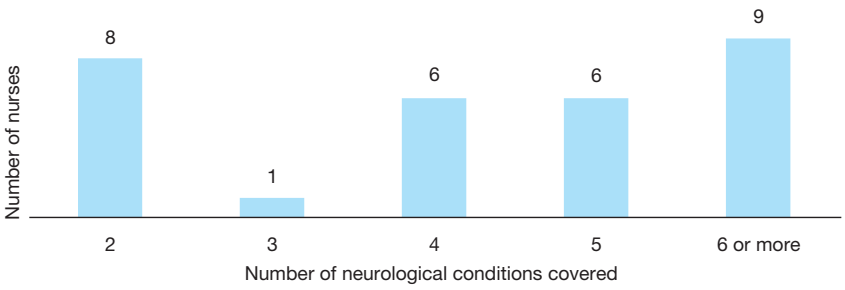


Of the 26 NSNs who answered the first survey, around half were employed in hospital Trusts and around half in community based organisations, but employing organisation made little difference to the settings in which they saw patients. 92% said that they undertake home visits, 85% said that they visit patients in residential and nursing homes, 77% hold clinics in hospital settings and 62% hold clinics in community settings.

Conditions covered by the NSNs

In addition to MS, the NSNs reported that they also covered between one and five other conditions, including MND, Parkinsons, Huntington's, Epilepsy and the 'Parkinson-plus' conditions (counted as one condition for the purposes of analysis) of multiple system atrophy (MSA), progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). One also reported covering neuromyelitis optica and two others said they covered 'other' conditions, but did not state what they were. The number of conditions (including MS) covered per individual is shown in the following chart.

Number of conditions covered per NSN



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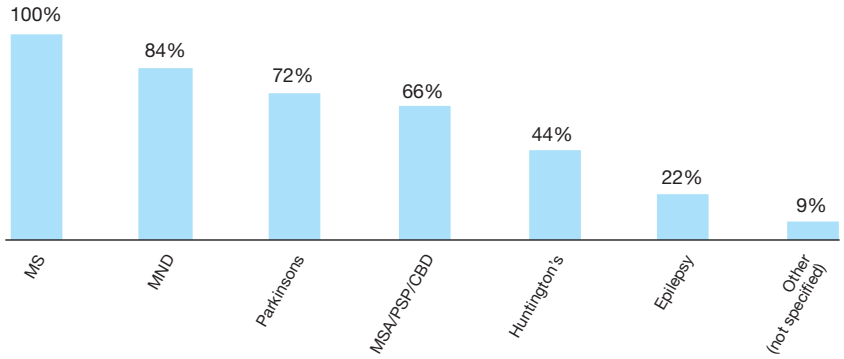
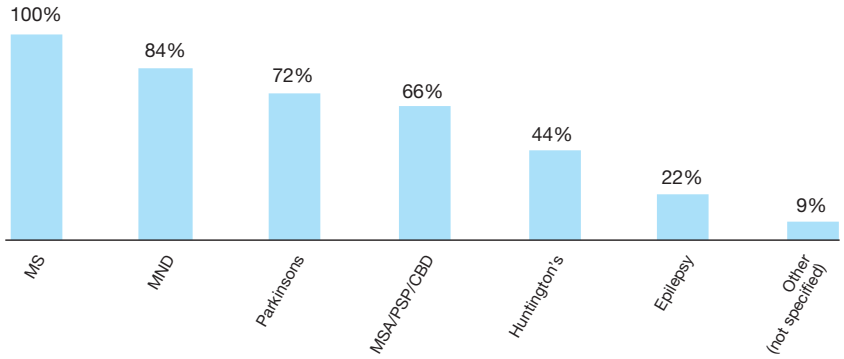
Looking at the groupings of conditions in the chart below, MS is most usually paired with MND, and rarely with epilepsy. Of the 8 NSNs covering two conditions, 5 covered MS and MND, 2 covered MS and Parkinsons, and one MS and epilepsy. The NSN covering three conditions covered MS, MND and Parkinsons. Nine NSNs reported that they covered all of the conditions.

% of NSNs covering this condition (n=32)



We asked the NSNs how much of their time they estimated that they spent on MS vs. the other neurological conditions they worked with. The answer ranged from 10% - 95% with an average of 48%. The average amount of time that NSNs covering each condition said they spent on that condition is shown in the chart below.

Proportion of available time that NSNs estimate that they spend on each condition (average response of those who cover that condition within their role) (n=30)



Some NSNs saw positive benefits to working across several conditions.

Development of the NSN role

Because NSN posts have not been systematically tracked in the way that, for example, MSSN posts have been, it is unclear whether the number of NSN posts is growing or shrinking and to what extent this forms part of a conscious strategy on the part of the NHS. In some areas, such as Norfolk, posts have been created as a planned response to the challenges of serving rural communities. In others, such as at the Walton Centre, the Foundation Trust has a stated plan to create a new cadre of 'Advanced Neurology Nurses', based in the community with links in to hospitals and able to support patients with a broad range of neurological conditions. However, in other areas, the development of posts seems to have been more ad hoc and evolutionary, resulting from specific local circumstances around funding and available skills.

NSNs views of their role

The six NSNs interviewed described their role in relation to people with MS in very similar terms to condition-specific MS Specialist Nurses. All described their role as extending from diagnosis, with the provision of information, education and support in coming to terms with it, through to the management of complex needs in people with progressive MS. All the NSNs interviewed played a role in managing and monitoring disease modifying therapies.

The NSNs had mixed views about covering multiple conditions within their roles. Some saw it as an inevitable consequence of the current NHS climate – something that they had been pushed towards to make their posts financially sustainable - while others saw it as a positive benefit to themselves and their patients to work across conditions.

The caseloads of those we interviewed varied from 265 at the lowest to 710 at the highest – a number which we have shown is around twice as many as can sustainably be managed by an MS specialist nurse, even without the added complexity of working across conditions[7]. A number of the NSNs were feeling overwhelmed by the volume of patients they were managing, and the interviewer tried to support them to separate issues of workload from issues to do with the mix of work.

Some of the benefits of mixed roles that NSNs cited were:

Increased flexibility in the workforce

Five of the six nurses we spoke to worked as part of small teams comprising NSNs and/or condition-specific nurses, and some said that they valued the flexibility in the team to enable them to cover one another, for example during holidays. The ability of the team to cover different conditions made it easier to adjust the balance of work in response to fluctuations in referrals of different conditions. There was also a recognition that the flexibility of the roles might make the posts less vulnerable to funding cuts.

> *"With two of us working across MS (one a joint post covering MS and epilepsy), it's easier to cover leave and variability in the service."*
>
> *"As the team leader, I took this role on partly to help me understand the roles of everyone I was managing – across MS, PD and epilepsy".*
>
> *"Because you are so busy, the role is less likely to be under threat and it's less likely that we will be asked to go on wards etc. We certainly feel a lot safer doing a mixed role."*

7. Modeling optimal MS specialist nurse caseloads, MS Trust 2014 (in press)

There is common ground between MND and progressive MS but less so with Parkinsons

Ability to cover a smaller geographic area

NSNs said that covering multiple conditions allowed them to cover a smaller geographic area than their condition-specific counterparts, reducing travelling times and enabling them to develop closer working relationships with other services (such as GP surgeries, nursing homes and rehabilitation teams) in their locality.

> *"It means that the patch is a reasonable size – though it's still 2.5 hours drive from Kings Lynn to the Broads. If we covered only one condition we would have to have an even bigger patch."*
> *Of Neurology nursing in rural Norfolk*

> *"There used to be condition specific nurses, but because the geographic area is very large and rural, it was a nightmare – you could spend all day travelling. It made more sense to split the geography and have individual NSNs relating to a number of GP surgeries, and to a large extent this has proved to be better."*
> *Again, an NSN in Norfolk*

> *"I enjoy covering all the conditions – and a big benefit in a rural area is that it means you aren't driving so far. We split up the GP surgeries between us and try to develop good working relationships with both surgeries and nursing homes in our patch."*

Opportunities to transfer knowledge between conditions

Many of the nurses said that there was a degree of overlap between certain aspects of managing the different conditions and that they were able to apply skills and transfer knowledge between them. This was seen as particularly true of MND and progressive MS.

> *"MND is incredibly similar to MS – effectively like highly active progressive MS. It's all about symptom management, baclofen, bowel care – all very similar."*

> *"There are no drawbacks we can see to doing a multi-condition role - other than that specialist nurses can regard you as a second class citizen – they think you can't possibly have the same level of knowledge as they do when they are only working with one condition. I would totally disagree. If there are challenges, it's about managing the size of caseload that we do, not about the mix of our caseload. In fact we feel very passionate and enthused."*

> *"Many of the issues are cross cutting - even between MS and Parkinsons. For example, swallowing difficulties might have different causes but have the same outcomes and treatment. We are always working with the same OTs and physios across the different conditions."*

> *"It's really good to cover multiple conditions if a patient has a differential diagnosis. There are many times where the knowledge I need crosses over from something I know from another condition. I'm discovering that a lot of the symptom management, psychological and social issues overlap – there is a lot of common ground."*

However, the 'common ground' was perceived as being less obvious between MS and Parkinsons and even less so between MS and epilepsy. Although we only interviewed one NSN who covered MS and epilepsy, she felt the overlap was minimal.

"It can be hard to know where to focus your time and to keep up to date with all the drugs"

"There are plenty of skills and relationships which are applicable across all the conditions – although MND and MS go much more closely together than with PD, where there is a huge number of drugs to learn."

"Our aspiration as a team is to go back to condition-specific nurses. MS and epilepsy are not natural bedfellows – epilepsy very much about education and medication, whereas MS involves much more multidisciplinary working and coordination of care."

Stimulation, challenge and respite from managing complex patients

Some NSNs said that they actively relished the variety and stimulation brought by managing multiple conditions. For some, the ability to work with, for instance, younger MS patients provided something of a 'break' from the very intensive work involved in managing people with complex needs: such as those with MND near the end of life.

"It's a healthy balance – we see newly diagnosed people where it's all about self-management and keeping people in work, others are at the end of life, some are young, some are old. This mix is healthy and satisfying – if you were just doing MND all the time it would be very draining."

Recognition that mixed roles are needed to cover rarer conditions

Some NSNs mentioned that, without their role, people with rarer conditions such as MND or Parkinson-plus conditions simply wouldn't have a specialist nurse to turn to, because patient numbers would be seen as insufficient to justify whole nursing posts. A sense of responsibility to all patients with long term neurological conditions inspired them.

"If we didn't do this role, people with rarer conditions like MND wouldn't get any support."

However, in contrast to the benefits, NSNs also highlighted a number of serious challenges in working with multiple conditions.

The difficulty of learning and keeping updated on the different conditions and treatments

The most obvious challenge of covering multiple conditions is the need to be up to date and knowledgeable about all aspects of the conditions and their treatments. 65% of the NSNs we surveyed said they covered four or more neurological conditions, which must present real challenges when it comes to the breadth of knowledge they are expected to have. Specialist nurses are expected to practice autonomously, at an advanced level, and to be able to deal with complexity. The range of drug treatments for MS, epilepsy and Parkinsons are constantly evolving and often involve complex regimens, requiring a high level of specialist knowledge. Linked to this, covering multiple conditions means relating to, and being a member of, multiple professional groups. This presents real issues, even for nurses working full time, but particularly given that over a third of the NSNs we identified work part time.

"It's tough – there is never a single moment to catch up. You have three lots of training and keeping up to date – it's not just one conference, one course. There are three lots of charities to link in with and a huge number of drugs to get to know and monitor. Caseloads if you are doing three conditions should be much smaller, but in reality they aren't."

"As a District Nurse I thought I knew a huge amount, but now I'm a specialist nurse, I know what I didn't know. PD involves a huge number of drugs which they are adjusting the whole time."

On why she wouldn't want to take on a third condition besides MS and MND

"It's hard to know where to focus your time and also which conferences and education meetings to go to – though in fact these tend to be MS because there is so much more support for MS specialist nurses."

"Doing one condition would be lovely in some ways – I'd love the time to be able to look into research and development, develop the service and myself, but I can never get the time."

"With a mixed role, it's hard to justify a significant investment in personal development in any one condition – for example I would love to do the MS degree, but I can't find the time or the money."

"What I miss is that I haven't got the time to do as much in-depth learning and professional development as I would like to. It will take me a lot longer to build up my knowledge on all the conditions as it would if I were only covering one."

"We ask for 2 years' neuro experience, but people won't necessarily have specific experience with all the conditions, so there is a huge amount of development they need to do when they start, which puts a lot of pressure on the more experienced nurses".

The risk that the very intensive conditions can 'take over'

Some of those interviewed felt that the very intensive nature of managing people with rapidly progressing conditions like MND meant that, at times, those with less urgent needs received less attention than they deserved and a more reactive than proactive service. Although MS Specialist Nurses could say the same thing about patients with advanced MS, mixing different conditions with very different disease trajectories presents particular challenges.

"The MND patients, while not numerous, are very challenging. Most MND patients have to be seen at home and I do 2-3 such visits per week. My main role is at diagnosis, and at each major deterioration, to involve other services and the MND Association visitors. In the last 6 months it is usually crisis management and often the family will contact me frequently by mobile phone… Since taking on MND, I can't say that I'm coping well or providing a gold standard service any more. The local MS Society want me to run a 'Getting to Grips' course but I just can't – I already work long days, and I'm not prepared to do more in the evening or at weekends."

"With a mixed role, MS patients can be short-changed because the other conditions can take over at times. This is partly about sheer workload, but also because of lack of focus."

The provision of condition-specific MS specialist nurses remains the ideal for people with MS.

Conclusions

This brief paper has highlighted some of the issues around developing Neurology Specialist Nurse roles. The challenges they face are significant, and, from the point of view of people with MS, it would seem that the provision of condition-specific MS Specialist Nurses remains the ideal – except possibly in very rural areas. Whether the number of these posts should be increased requires further consideration and debate, and further posts should not be created without a full consideration of the consequences. Delivering Neurology Specialist Nurse services well involves additional requirements to ensure they are able to deliver a high quality service to all conditions. This includes enough posts to ensure manageable caseloads, sufficient protected time (both on appointment and ongoing) for keeping their knowledge up to date across all the conditions they work with, and the availability of expert input from, for example, neurologists and condition-specific nurses with more in-depth expertise in each condition.

A concern is that the training and professional support structures for the NSNs may be less well-developed and straightforward than they are for condition-specific nurses. We would recommend that all patient organisations and professional groups identify those NSNs who cover conditions that they represent and offer them the same support and input as the condition specific nurses receive.

telephone: 01462 476700

For further information on this report and work by the MS Trust on MS specialist nursing and other services, please contact Amy Bowen, Director of Service Development (amy.bowen@mstrust.org.uk).

Acknowledgements

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About the MS Trust and this survey

The MS Trust is a national charity which works to make a real difference to people with MS.

For over 10 years, the MS Trust has run a national programme of education, education bursaries, mentoring and professional development for health professionals working with people with MS. The programme focusses principally on MS specialist nurses (MSSNs) and on allied health professionals (AHPs) working in MS. The education events, bursaries and mentoring elements of the programme are funded through investment made by the MS Trust and the Department of Health Risk-sharing Scheme.

The MS Trust has a close relationship with most of the MSSNs in the UK. The Trust keeps an up-to-date database and map of MSSNs, to help signpost people with MS to their nearest MSSN as well as to monitor availability of services. The MS Trust has a high degree of confidence in the comprehensiveness of the MSSN database.

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Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. **info@mstrust.org.uk**
www.mstrust.org.uk

Registered charity no. 1088353

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