

SOUTH BANK UNIVERSITY, LONDON

MS RESEARCH TRUST



Evaluation of MS Specialist Nurses

A Review And Development of the Role

Executive Summary

- Part I** **Report on the National Survey of Multiple Sclerosis
Specialist Nurses in the UK**
- Part II** **Case study of a new multiple sclerosis specialist nurse
service in West Berkshire, England**

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FACULTY Of HEALTH - June 2001

ACKNOWLEDGEMENTS

Research assistance to the project was provided by Jackie Farrow (Senior Lecturer), Karen Giles (Principal Lecturer), Ben Gray (Research Fellow), Maria Lorentzon (Honorary Senior Research Fellow) Kathryn Robinson (Research Fellow) and research advice by Ann Taket, Professor of Primary Care, all at the Faculty of Health, South Bank University.

EXECUTIVE SUMMARY

1. Background

- The project was commissioned by the MS Research (Charitable) Trust and jointly funded with South Bank University.
- The purpose of the project was to review and describe the UK MS Specialist Nurse's role and to identify evidence of Specialist Nurses' contribution to MS care from a variety of perspectives.
- An estimated 85,000 people in the United Kingdom (UK) have multiple sclerosis (MS), with a further 2,500 being diagnosed each year. It is the most common cause of acquired disability in young adults and is characterised by variation and uncertainty. Managing uncertainty is acknowledged to present major challenges in living with chronic illness (Cohen, 1993).
- The needs of people with MS are often left un-met by current NHS services (Robinson and Hunter 1998, Nodder et al 2000).
- The need for knowledgeable "link-workers", in most cases Specialist Nurses has frequently been identified in the literature (British Society of Rehabilitation Medicine 1993) but few in-depth studies of specific UK Specialist Nurse groups are available. These roles need careful evaluation (Humphris 1994, 1999).
- In the literature, stress is placed on the importance of patient information, the need for patient advocates and knowledgeable link workers, who are easily accessible, quick to respond and in some cases make home visits. It is suggested that from the patient's point of view, the MS Specialist Nurse is well placed to take on this role (Kirker and Young 1995, Wahlquist 1984, Winters et al 1989).

2. Project outline and aims

The two clear elements of the project consisted of:

- *A national survey* (postal questionnaire) of all MS Specialist Nurses, or nurses spending the larger proportion of their time specifically on MS care.

Aim: To make the role of UK MS Specialist Nurses explicit and suggest recommendations for the development, support and educational requirement of these posts through an exploration of nurses' perceptions of the current role.

- *A multiple methods, developmental case-study* based around the service of a newly appointed MS Specialist Nurse in West Berkshire.

Aim: To develop and demonstrate the effectiveness of an MS Nursing Service, based on the needs of the local MS population and other associated stakeholders, using a variety of methods.

3. Methods

3.1 *UK National Survey*

The objectives of the survey were:

- To explore the professional profiles of MS Specialist Nurses in the UK.
- To identify how MS Specialist Nurses are employed and managed.
- To investigate the educational backgrounds and needs of MS Specialist Nurses.
- To determine what support systems are available/needed by MS Specialist Nurses.
- To identify how MS Specialist Nurses work with others and what contribution they make to the care of people with MS.
- To determine what MS Specialist Nurses say about the clinical effectiveness and job satisfaction of such roles.

3.2 *Developmental case study*

The main elements of the case study were:

- Twenty-four semi-structured interviews with two sets of 12 people with MS, spanning the four disease phases outlined by the MS Society Standards of Healthcare, exploring their experiences and perceptions of service need before and after the availability of a local MS Specialist Nurse. A number of carers also participated.
- Nine semi-structured interviews and attendance at a Primary Care Group Clinical Forum (involving 22 participants) to consult associated professional "stakeholders". The Forum included General Practitioners (GPs), district nurses, a pharmacist, a neurologist, a consultant in neuro-rehabilitation and the MS Specialist Nurse.
- Development and auditing of two structure, process, outcome style Standards, based on priorities agreed by the local "stakeholder" Steering Group related to (i) diagnosis and (ii) the education of formal (paid) carers.
- A comparative, retrospective review of MS hospital admissions through analysis of medical records.
- A reflective diary maintained by the MS Specialist Nurse.
- A detailed two week diary of MS Specialist Nurse activity.
- A period of service development, using an action research approach involving the researcher and the MS Specialist Nurse, influenced by perceptions of need identified from the data and ratified by the Steering Group.
- Active involvement in project planning and prioritisation by the local "stakeholders" Steering Group.

3.3 Data Analysis

- Qualitative and quantitative data analysis techniques were used for the national survey and the case study depending on the different methods used.
- Statistical data were analysed using the Minitab statistical package.

3.4 Ethics

- Ethics committee approval was obtained from the University for the survey and from the Local Health Authority for the case study. The project was regulated by the Data Protection Act and registered with the University data protection officer.

4. Findings: UK National survey

- The response rate was 61.4%. In the main, MS Specialist Nurses in this sample were very experienced nurses (mean length of time since qualification was 13.5 years), with an expressed commitment to empowering people with MS and their families to regain a feeling of control in living with the disease. Interventions were summarised as addressing five main patient problems:
 - getting care or accessing services,
 - finding information,
 - the need for psychological care, support and counselling,
 - symptom management,
 - problems associated with a general lack of awareness of MS.
- In positive terms:
 - MS Specialist Nurses provided support from the time of diagnosis and throughout the illness trajectory.
 - They formed a direct two-way link between the community and neurologists/the acute care team.
 - MS Specialist Nurses helped ward staff co-ordinate complex hospital discharges.
 - They often supported patients in their management of beta interferon treatment.
 - They were actively involved in local educational initiatives, seeing teaching as one of the most important aspects of their role.
 - The opportunity to practise more holistically as a nurse was highly valued.
- However the role was identified as:
 - very complex, isolating and exhausting, with no boundaries and with a significant risk of "burn out".
 - often having unrealistic caseloads, and lack of support, specifically Clinical Supervision.
 - In addition there were considerable discrepancies in the grading of some MS Specialist Nurse posts.
- Although generally satisfied with the effectiveness of nursing care possible in the role, and with the job itself, MS Specialist Nurses were aware of improvements to the way in which such roles are set up which could make it less frustrating and more sustainable for newcomers to the speciality.

5. Findings: Developmental case study

5.1 Patient interviews

- The respondents displayed similar characteristics in terms of gender ratio, age
- range and age at onset of symptoms to the "typical" profile of people with MS (Robinson et al 2000)
- The majority of the respondents had received their diagnosis from local neurologists
- The diagnosis, the time leading up to and following it, were for most a very difficult time, arousing strong emotions, including fear, anger, shock/devastation, abandonment/isolation and occasionally relief. This was the case in three patients who had suspected they were suffering from a brain tumour rather than MS
- Possible explanations for some of these findings include:
 - that differing patient and professional perspectives co-exist (Robinson, 1990),
 - that there was frustration on the part of patients with the knowledge base of professionals,
 - that the timing for patients taking in information was not always right, that there was sometimes not enough contact with other people with similar MS problems around the time of diagnosis,
 - that more holistic support was not available to address non-medical issues.
- Those who had had contact with the MS Nursing Service at or around the time of diagnosis, had found it to be very helpful in terms of both support and information given
- Comparative data suggested the concept of "abandonment by the healthcare system" which was a prominent feature before the establishment of an MS Specialist Nurse, was mitigated following her appointment
- Further comparative data implied there was a growing awareness, contact with and access to the MS Specialist Nurse describing her as:
 -
 - an ongoing source of support and information for people and their carers at subsequent phases of the disease and not just at diagnosis,
 - an emotional resource for spouses or partners and other family members,
 - adviser to and educator of non-specialists such as GPs, hospital and community nurses and home care assistants,
 - a "lynchpin" and link with other professionals, who was well placed to act as an overall service co-ordinator,
 - requiring a team to assist her to manage the increasing demands of her role.
- GPs and hospital doctors featured as sources of help throughout the disease trajectory, although mixed experiences were reported.
- The key role of specialist physiotherapists in treatment was emphasised.

- Occupational therapists were said to be "very helpful" and supported daily living activities by advising on and arranging equipment and home adaptations.
- Social Service departments were described as key to "the wellbeing of MS patients" by providing home care and mobility assistance inside and outside the home.
- The availability of disabled friendly transport and easy access to public places was viewed as currently restricted but an essential source of help.
- Education for people with MS, the general public and their lay carers was viewed as very important.
- The role played by spouses or partners both at the time of diagnosis and later in terms of continued care and support, in some cases over many years, could not be overestimated.
- More general support for family carers was seen to be required.
- Easier access for patients to specialist treatment (e.g. beta interferon) and care was said to be needed.

5.2 Stakeholder interviews

Consultations with stakeholders in the local management of MS and in the MS Specialist Nurse's service were very positive about the potential to make a difference in MS care. Perspectives focused mainly on:

- Patterns of care for people with MS e.g.:
 - quality of contact between organisations;
 - communication and liaison between professions;
 - economic and financial difficulties;
 - organisational change;
 - psychological problems and the vulnerability of professionals, in terms of their own lack of knowledge and skills working with some people with chronic illness;
 - appropriate supervision, support and education of professionals;
 - the ways in which MS Specialist Nurses augmented care,
 - problems with the delivery of health and social services.
- The employment of an MS Specialist Nurse was said to increase the emphasis on holistic care and chronic disease management.
- The MS Specialist Nurse was seen as an expert in palliative care.
- The MS Specialist Nurse was seen as the natural "key worker" (e.g. in relations with Primary Care Groups/Trusts).
- The MS Specialist Nurse was seen to be in a position to cascade information about MS to professionals, carers and families of people with MS.
- Stakeholders gave key service recommendations on ways forward in developing MS care and supporting the delivery of MS nursing services.

5.3 Development and audit of two local standards

The Steering Group decided on two priority standards that should be formally audited from a variety of perspectives.

- Audit of standard of management at and after diagnosis:

Three sets of evidence were scrutinised:

- medical records,
- nursing records,
- patient satisfaction questionnaires.

Each set of evidence is summarised below.

- A sample of nine sets of medical records on each occasion:
 - The intervals between receipt of GP referral and first appointment with the neurologist were identical in 2000 and 2001 and in both cases over half the sample (5/9) had appointments with the Neurologist within 1-4 weeks of GP referral. No patient waited longer than 12 weeks for an initial appointment.
 - In the first sample 66.6% completed investigations and were told their diagnosis within eight weeks of the initial consultation. This increased to 88.8% in the second sample. All patients in the first sample and all but one in the second received their diagnosis from a Consultant Neurologist as per MS Society and local standards.
- A sample of nine sets of nursing records on each occasion:
 - In 2000, 33.3% of patients had contact with the MS Specialist Nurse within seven days of diagnosis, as identified by the standard. In contrast, none of the second sample had contact with the MS Specialist Nurse within the first seven days after diagnosis, but this was replaced by more consistent contact (77.8%) within one month of diagnosis.
 - Overall, written records suggested the pattern of the MS Specialist Nurse's service to newly diagnosed patients changed over the audit period, probably to accommodate the demands of a developing caseload.
- Satisfaction questionnaires sent to two groups of 20 randomly selected newly diagnosed patients:
 - Twenty nine patients were invited to attend "Getting to Grips with MS" courses during 1999, and this increased by over a third to 39 in 2000.
 - Almost two thirds of patients (61.5%) in the first sample felt the explanation of MS from the doctor at the time of diagnosis was too brief. This improved in the second sample, but just over half (53.8%) still felt that explanations were too brief. Those who felt it was about right increased from 38.5% to 46.2% in the second sample.

- The feeling of abandonment by the healthcare system was an obvious feature of the first set of comments, but less marked in the second.
 - Overall, there was evidence of service improvement from the three perspectives studied. Patients' comments gave a clear indication of the valuable role that many of them felt the MS Specialist Nurse had played in giving information and support around the time of diagnosis.
- Audit of the MS Specialist Nurse's involvement in educating formal carers:

Two sets of evidence were scrutinised:

- Evaluation forms from a carers' educational programme.
 - Questionnaires from hospital nursing staff.
- The MS Specialist Nurse and County Council Training Officer responded to carers' requests and jointly planned a programme to meet group needs. This was well evaluated with 30 respondents rating it as excellent (score 5) and 19 rated it as good (4). Only one rated it average (3).
 - Comments indicated that community carers had a greater understanding of the effects of MS on the individual and family as suggested by qualitative comments.
 - Hospital nurses did not receive, but would have liked formal training in the care of people with MS but also considered that the MS Specialist Nurse's advice/support positively affected their care delivery.
 - Responses to the Registered Nurse Questionnaire, indicated they would contact her when a patient with MS was admitted, especially as they were now aware of how she could help. They viewed the MS Specialist Nurse's role as advising not only the patients but also themselves.

5.4 Review of hospital medical records

- Differences in the pattern of MS patient admission were identified between the 12 month period directly before employment of an MS Specialist Nurse, compared with a 12 month period commencing after the MS Specialist Nurse had been established for six months.
- Reduction in the rate of emergency rather than elective hospital admissions, a reduction in length of stay and a shift away from predominantly acute general medical ward admissions towards rehabilitation, neurology or Young Disabled Unit care was found.
- In addition to likely qualitative benefits for patients and their families, these changes showed considerable cost benefits to the Trust.
- A simple calculation of reduced cost, as indicated by a comparison of bed occupancy between the two years amounted to £104,329.65.
- Although it is acknowledged that other hidden cost factors may be involved, when the cost of employing an MS Specialist Nurse for one year was offset against this sum, a total saving of £64,611.45 remained.

- It is proposed that the establishment and active involvement of an MS Specialist Nurse, providing a focus of expertise, leadership and a combination of direct and indirect intervention may have contributed to the observed differences in patient admission patterns in the two sample years.

5.5 MS Specialist Nurse's Reflective diary

- Recordings of the MS Specialist Nurse's audio diary were used to identify a series of critical incidents in which she had played a key role.
- The incidents covered a range of complex psychosocial and physical interventions with clearly identified outcomes.
- Some of these outcomes included delaying the hospitalisation of a severely disabled patient so that she could stay home longer with her children, resolving problems of incontinence and constipation, reducing the risk of aspiration pneumonia and arranging respite care.

5.6 Detailed diary of MS Specialist Nurse activity

The diary provided a useful "snapshot" of the relative frequency of various interventions.

- The MS Specialist Nurse kept a two week detailed diary, recording her activities in terms of the people she contacted, the venues and timings involved.
- In the breakdown of activities, psychosocial interventions (32) were most common followed by physical (19), social (16) and information giving/education (8). In terms of activities, the most common was telephone work, followed by patient contact in clinic, home or ward and patient related meetings/discussions.
- Teaching/preparation, contact with relatives and administration were the next most frequent cluster of categories with activities associated with own professional development being recorded once during the two week period.
- The MS Specialist Nurse recorded a number of outcomes from her interventions during the first week, which involved negotiation and liaison with a variety of agencies on behalf of patients or carers. These outcomes resulted in initiation or a change of treatment to control symptoms, obtaining information or benefits for patients and/or their families.

5.7 Service Development

- The stakeholder Steering Group formed an important reference point and focus for discussion regarding the MS Specialist Nurse's service, and the wider picture for people with MS in West Berkshire.
- Meeting at two monthly intervals throughout the project, this was a well supported, mutually beneficial opportunity to pool experience and ideas, promoting effective care for people with MS, providing a strong local drive for the project and enhancing group members' understanding of the local systems and dilemmas in MS care.

- Arising from common issues in qualitative interview data from patients and stakeholders, the Steering Group decided on two priority standards (see section 5.3 above) that should be formally audited from a variety of perspectives during the project.
- Through use of a detailed structure/process/outcome approach it was possible to identify and develop strategies to close gaps in service provision and to demonstrate positive outcomes following MS Specialist Nurse activity.
- These tools were recommended for use as part of routine clinical audit and to serve as a template for the development of other standards beyond the time span of the project.
- The period of service development gave further time for the MS Specialist Nurse to establish her service and make an impact on local MS care.

6. Conclusion

- This multi-faceted study has attempted to explore the developing role of MS Specialist Nurses, using a variety of methods and perspectives, paying particular attention to the views of service users and the post-holders themselves.
- Joint evidence from the case study and survey suggests that the service offered by MS Specialist Nurses attempts to address the needs that have frequently been highlighted as unmet by previous NHS services. These include the lack of information, fragmentation and lack of continuity in services, poor understanding of the disease among professionals and lack of psychological support, particularly around the time of diagnosis.
- People with MS experienced strong emotions around the time of diagnosis including abandonment/isolation; shock/devastation, fear and frustration with the perceived lack of professional knowledge. They wanted professionals to understand that MS is a unique experience for each individual requiring an individualised response. Support for partners and family was also seen as vital.
- Patients and neurologists had differing expectations of how the process of diagnosis and subsequent support should be managed. GPs played a role throughout the illness trajectory but with variable effect, depending on their level of expertise and interest.
- The MS Specialist Nurse provided a bridge between patient and professionals both at the time of diagnosis and in the long-term management of MS. The documentation of critical incidents demonstrated the impact she could have on patient outcomes. Stakeholders experienced the employment of the MS Specialist Nurse as increasing the emphasis on holistic care, chronic disease management and improving liaison between the primary and secondary care sector.
- There is additional evidence that employment of an MS Specialist Nurse can have a significant effect on patterns of MS patient management in hospital, with cost saving implications.
- The study has also highlighted some important issues surrounding the effective management, support, educational and developmental needs of MS Specialist Nurses, given their role as relatively independent practitioners, working in a job which is very complex, isolating and exhausting, with no boundaries and with a significant risk of "bum out". Added frustrations relate to the disease itself, where there are no clear answers or total resolution of symptoms.

- The research design demonstrates one approach to exploring and evaluating the complexity of specialist nursing intervention and has highlighted some issues which are responsive to MS Specialist Nursing involvement. It has also provided a potential framework and tools for auditing the service as part of clinical practice, beyond the span of the project.
- The value of systematically involving users or "stakeholders" in reviewing, planning, developing and evaluating services has also been demonstrated. This was shown to be a mutually beneficial activity which enhanced care planning and the research process.

7. Recommendations and the way forward

- **Specific to MS Specialist Nurses:**

1. At the time of diagnosis, support systems such as MS Specialist Nursing services should be put in place to bridge the gap between patient and physician expectation and to meet a variety of medical and non-medical needs in the longer term management of MS.
2. Consideration of the number of MS Specialist Nurses required nationally so that all people with MS have the potential to access these services, and to ensure that MS Specialist Nurses have manageable workloads.
3. Ensure parity of access to the MS Specialist Nurse in both the public and private sector.
4. National and local clarification of the scope and responsibilities of the role for the benefit of the potential post-holder, managers, other nurses and the multi- disciplinary team.
5. Within the new NHS pay system, recognition of the demanding nature of the role and the development of skills and experience from novice to expert MS Specialist Nurse, through clearly identified competencies. This should also extend to include some posts at Consultant Nurse level.
6. Longer term contracts where possible to allow for forward planning, capitalising on MS Specialist Nurses' skills in leading service developments and enhancing job satisfaction.
7. Management recognition of the need for mentoring and supervision systems in place to support MS Specialist Nurses and prevent burnout in their demanding role.
8. Networking opportunities for support, professional development and to encourage innovation.
9. Recognition that MS Specialist Nurse roles should be seen in relation to local Trust/organisational business planning strategies to maximise effectiveness and enhance visibility. A core set of MS Specialist Nurse audit data to be developed locally and routinely collected to best represent the impact and effectiveness of the role.
10. Availability of recognised courses and study days in preparation for the role and as continuing education, covering, for example, specialist clinical MS issues, working with acute and community "systems" and internal politics, autonomous nursing practice and information technology / administration / time management skills.
11. Close liaison, joint visits and meetings between the MS Specialist Nurse, the Primary Care Trusts and members of the primary care team, in particular GPs and district nurses.
12. A 24 hour telephone line to extend the MS Specialist Nursing service.

13. Where possible, the MS Specialist Nurse to extend her educational role to the public as well as lay carers of people with MS.
14. Ensure mechanisms to support patients and their partners to attend "Getting to Grips with MS", "Taking Control" or other similar courses for the newly diagnosed.
15. Ongoing joint planning and monitoring of educational programmes between the MS Specialist Nurse, Social Services and the hospital sector so that MS Specialist Nurses play a key role in the education of non-specialist practitioners.
16. Mechanisms for service development and joint working to be set up across a range of stakeholders as exemplified by the Steering group members who met on a regular basis throughout the span of the project.

- **More general recommendations:**

17. Understanding and appreciation on the part of professionals that MS is a unique experience for each individual, requiring an individualised response.
18. Encouragement of patients to bring personal support with them at the time of diagnosis.
19. Appreciation by neurologists that patients are in a period of transition when they are first given a diagnosis of MS and to consider routine follow-up appointments.
20. Appropriate timing and availability of good quality information by service providers to patients to allow them to play an active role in their care.
21. Availability of information packs about MS on hospital wards, nursing homes, social services and private care agencies.
22. Training of non-Specialist Nurses and home carers on a routine basis to meet the needs of people with MS at different stages of the illness trajectory e.g. in the provision of respite care.
23. More respite care for people with MS and their families.
24. Greater support and help for the carers of people with MS, such as that provided by the specialist voluntary sector.
25. Set up record systems to improve information exchange between patients, professionals, the public, private and voluntary sector.

References

1. British Society of Rehabilitation Medicine. Working Party report on Multiple Sclerosis. 1993. London.
2. Cohen, M.H. The unknown and the unknowable - managing sustained uncertainty. *Western Journal of Nursing Research* 1993; 15:77-96
3. Humphris, D. The basis of role specialisation in nursing. In: *The Clinical Nurse Specialist: issues in practice*, edited by Humphris, D. London: Macmillan, 1994; 1-15.
4. Humphris, D. A framework to evaluate the role of nurse specialists. *Professional Nurse* 1999; 14:377-379
5. Kirker, S. and Young, E. An evaluation of a multiple sclerosis liaison nurse. *Clinical Rehabilitation* 1995; 9:219-226
6. Nodder, D. Chappell, B. Bates, D. Freeman, J. Hatch, J. Thomas, S. and Young, C. Multiple sclerosis: care needs for 2000 and beyond. *Journal of the Royal Society of Medicine*, 2000,93 (5): 219-24.
7. Robinson, I. (1990) Personal narratives, social careers and medical courses: analysing the trajectories in autobiographies of people with MS. *Soc. Sci. Med.*, 1990; 30, 1173-1186.
8. Robinson, I. and Hunter, M. Views from the other side: everyday perspectives on living and working with MS by those concerned with their formal and informal (health) care. Report for the Multiple Sclerosis Society of Great Britain and Northern Ireland. 1998.
9. Robinson, I. Neilson, S. and Rose, F.C. *Multiple Sclerosis at your fingertips*. London: Class Publishing, 2000.
10. Wahlquist, G.I. Impact of a nurse managed clinic in multiple sclerosis. *Journal of Neurosurgical Nursing*. 1984; 16:193-196
11. Winters, S. Jackson, P. Sims, K. and Magilvy J. A nurse-managed multiple sclerosis clinic: improved quality of life for persons with MS. *Rehabilitation Nursing*. 1989; 14:13-16