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**Rapid review**

# The role of specialist nurses in multiple sclerosis: a rapid and systematic review

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**Health Technology Assessment**
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# The role of specialist nurses in multiple sclerosis: a rapid and systematic review

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# Contents

# List of abbreviations

| | |
|---|---|
| AMED | Allied and Complementary Medicine Database |
| ASSIA | Applied Social Sciences Index and Abstracts |
| BIDS | Bath Information and Data Services |
| BNI | British Nursing Index |
| CCTR | Cochrane Controlled Trials Register* |
| CDSR | Cochrane Database of Systematic Reviews* |
| CNS | central nervous system |
| CRD | Centre for Reviews and Dissemination* |
| DARE | Database of Abstracts of Reviews of Effectiveness* |
| HMIC | Health Management Information Consortium |
| MeSH | Medical Subject Headings* |
| MS | multiple sclerosis |
| NCCHTA | National Coordinating Centre for Health Technology Assessment* |
| NHS EED | NHS Economic Evaluation Database* |
| NICE | National Institute for Clinical Excellence |
| NLM | National Library of Medicine |
| NRR | National Research Register* |
| RCN | Royal College of Nursing |
| RCT | randomised controlled trial |
| SCI | Science Citation Index |
| SSCI | Social Sciences Citation Index |

* Used only in appendices

# Executive summary

## Background

Multiple sclerosis (MS) is a disease of the central nervous system. The cause is unknown. There are about 80–160 people with MS per 100,000 population, with twice as many women affected as men.

The management of individuals with MS includes treatment of acute relapses and chronic symptoms. The care of MS patients is provided by various healthcare professionals, such as general practitioners (GPs), neurologists, physiotherapists, occupational therapists and nurses. Some MS patients have access to an MS specialist nurse, although this provision varies geographically.

## Objectives

The aim of this report is to assess the effectiveness and relative cost-effectiveness of MS specialist nurses in improving care and outcomes for patients with MS.

## Methods

A systematic review of the literature, involving a range of databases, was performed. Full details are described in the main report.

## Results

Only one study was identified that tried to evaluate the benefit of MS specialist nurses. The study concluded that MS patients and their carers found the MS specialist nurse to be helpful, particularly in improving their knowledge of MS, ability to cope, mood and confidence about the future. GPs also reported finding the nurse to be helpful with their MS patients, and 40% of the GPs stated they would purchase the services of an MS specialist nurse if their practices became fundholding. However, there were considerable methodological weaknesses inherent in the study design, and it was unclear whether the results of the study could be extrapolated to other settings or to other MS patient groups.

### Ongoing research

There are two ongoing research studies regarding MS specialist nurses. One of these studies involves the provision of MS nurses to several areas, but also has two control populations to allow evaluation of the health benefits of the nurses to MS patients and their carers. This study will help to fill the evidence gap.

### Costs

The costs of providing MS specialist nurses consist of their yearly salary (usually NHS grade G), as well as additional costs for travelling, administration, computer and telephone use, a pension scheme, National Insurance and study leave. The MS Society of Great Britain and Northern Ireland allows a generous total yearly cost to the employer of £40,000.

## Conclusions

The present evidence does not make it possible to comment with any certainty on the value of specialist nurses in MS. The best evidence available to the authors is specialist opinion from neurologists and nurses, and comments from patients with MS; this opinion supports the provision of MS specialist nurses.

### Recommendations for research

Further research is needed before it will be feasible to make firm recommendations on the value of MS specialist nurses relative to other possible uses of funds.

# Chapter 1

## Aim of the review

The aim of this review is to assess the effectiveness of specialist nurses in improving the care and quality of life for patients with multiple sclerosis (MS).

The role of specialist nurses in MS includes the provision of information and support, at diagnosis and during relapses, to both patients and carers. MS specialist nurses are also responsible for co-ordinating the healthcare (and possibly social services care) for patients with MS as well as the education of primary healthcare and Social Services Department staff. In recent years, there has been a rapid rise in the number of specialist nurses in MS, some of whom are partially funded by the MS Society of Great Britain and Northern Ireland, or the pharmaceutical industry, with the expectation that health authorities will eventually take over all the funding.

# Chapter 2

# Background

## Description of underlying health problem

MS is a disease of the brain and spinal cord. The cause is unknown. The symptoms of MS include muscle weakness, disturbances of sensation, fatigue, incoordination of movement, spasticity, pain, incontinence, cognitive dysfunction and mood disturbance.

MS usually presents with an episode of neurological dysfunction, often attributable to inflammation at one or more sites within the central nervous system (CNS). Such presentations include visual loss due to optic nerve involvement, blurred vision due to brain stem involvement, and disturbances of sensation, muscle weakness and incontinence due to spinal cord lesions. The 1993 report of a working party of the British Society of Rehabilitation Medicine provides a good review of the problems caused by MS.[1]

There are four patterns of disease.

1. In the relapsing–remitting MS form, patients have discrete motor, sensory, cerebellar or visual attacks that come on over a 1- to 2-week period and often resolve over a 4- to 8-week period, with or without treatment.[2] Some patients accrue disability with each episode or exacerbation, while remaining clinically stable between relapses. Others have many years of unrestricted activity punctuated by short-lived disturbances that resolve completely. About 85% of patients initially experience this form of MS, but within 10 years 50% of patients go on to develop the secondary progressive form.[3]
2. In the secondary progressive form of MS, patients who previously had relapsing–remitting MS experience gradually increasing disability, with or without discrete relapses.
3. Primary progressive MS with unrelenting advancement of the disease, though at variable rates over months or years,[4] is experienced by approximately 15% of patients.[3]
4. A small proportion of patients with MS have a benign course with minimal disability after 10–15 years.

The prevalence of MS in the UK varies geographically, from around 80 to 160 per 100,000 population, with twice as many women affected as men.[5]

At the onset of disease, most patients will have a relapsing–remitting course; after two or three decades, a large proportion will have converted to progressive disease. Patients' needs will vary according to whether they are having a relapse or are in remission, and what stage of the disease they have reached.

The forthcoming Trent Institute for Health Services Research report on the natural history of MS[6] will supply more information, but *Table 1* shows the estimated prevalence of the two main categories of MS within a typical health authority.[6,7]

## Current service provision

The MS Society performed a postal survey of 223 patients with MS and reported in 1997 that 85% of patients saw a general practitioner (GP), 66% a neurologist and 45% a physiotherapist or occupational therapist.[8] A limited proportion of

**TABLE 1** *Average health authority: estimated number of patients with MS*[6]

| Form of MS | Approximate proportion of MS patients | Estimated prevalence* | |
|---|---|---|---|
| | | Minimum | Maximum |
| Any form of MS | 100% | 400 | 800 |
| Relapsing–remitting MS | 45% | 180 | 360 |
| Secondary progressive MS | 40% | 160 | 320 |

* *Patients with MS per health authority, based on an average population of 500,000 and prevalence of 80–160 affected patients per 100,000 population*

patients consulted complementary/alternative therapists (15%), MS or neurology specialist nurses (13%), or specialists in rehabilitation medicine (8%). It was rare for patients to have been referred to continence advisers, urologists, pain specialists or clinical psychologists (< 2% per group). It is unclear from the survey whether respondents saw the different practitioners during the previous 1 year, 2 years or longer. It should be noted that service usage may vary with the severity of the patients' condition.

Hence, at that time, only a minority of MS patients had access to an MS specialist nurse, and there is still marked geographical variation in provision. Furthermore, many of the posts are funded from 'soft money'.

Data provided by the MS (Research) Charitable Trust (Letchworth, UK) show that, in 1993, there were only three specialist MS nurses in the UK. In 1995, Schering Health Care funded an additional 30 posts.

The MS (Research) Charitable Trust supports educational programmes and a database of specialist nurses, but does not fund the salaries of nurses.

## Description of new intervention

A Clinical Nurse Specialist refers to "a registered nurse, who, after a significant period of experience in a specialised field of nursing and with additional nursing education, is authorised to practise as a specialist with advanced expertise in a clinical speciality to involve clinical practice; consultation; teaching and research".[9] MS specialist nurses should be distinguished from other nurses giving support to MS patients or doing MS work (While A, King's College, London: personal communication, 2000). There are approximately 70 MS specialist nurses in the UK at present, some of whom are funded by the NHS, some by the MS Society and others by the pharmaceutical industry.[10,11] Currently, the MS Society is part-funding up to 33 new MS specialist nurse posts, which will be spread throughout the UK. There are also other neurology specialist nurses who may spend a proportion of their time with MS patients and who may be community based.

MS is frequently diagnosed when patients are at the peak of their careers, between the ages of 20 and 40 years,[12] and is the commonest acquired cause of severe disability in young adults.[1] Doctors are often poor at recognising handicaps[13] and incontinence,[14] and patients may not spontaneously report these problems to them.[15] Given the small number of patients with MS in each practice, GPs cannot be expected to be experienced in all the problems associated with the condition.[16] Specialist nurses can therefore be a link between primary and secondary healthcare teams and an important source of access to services.[17]

MS specialist nurses are mainly based in acute hospitals, in addition to a few in smaller hospitals and one hospice (Haffenden S, MS Society, London: personal communication, 2000). The role of the MS specialist nurse involves support for patients in the home and at clinics.[18] Patients have reported that it is easier to talk to the specialist nurse in their homes than to a doctor in the outpatient clinic, where they feel embarrassed talking about sensitive matters such as incontinence or sexual dysfunction.[19] The MS specialist nurse can provide continuity of support from early presentation, when diagnosis is established, to the management of a different lifestyle when MS symptoms start imposing limitations. Therefore, part of the role of the MS specialist nurse involves working on personalised plans for people with MS.[11]

One issue is geographical access to MS specialist nurses. Because MS specialist nurses are usually based around neurology departments, there are problems of access for rural areas. However, in certain parts of the UK, there is a waiting time of 6–9 months, even in areas where there is a nurse. Thus, first-time referral can be a problem (Haffenden S, MS Society, London: personal communication).

Due to the current lack of information on the number of MS nurses and their role, the authors carried out a rapid and very brief questionnaire survey. The aim was not to do a detailed study with publishable results, but only to obtain a snapshot of current activities, as background to the review. A total of 69 postal questionnaires (see appendix 1) were sent out by the MS (Research) Charitable Trust to the existing MS specialist nurses around the UK who spend 100% of their time on MS. Twenty-six questionnaires were returned and analysed. The survey contained questions on the activities MS nurses take part in, how much time they spend in each of the various roles they perform, and which activities they would take on or reduce if they had more or less time available.

The results showed that the three main uses of time were providing information, education and advice to patients and their carers; providing psychological support; and community follow-up visits. If these nurses had more time available, they would spend more time with their patients and felt that they would deliver a better service. More details are given in appendix 2.

# Chapter 3

# Effectiveness of MS specialist nurses

## Methods

The *a priori* methods for this review are given in the protocol approved by the National Institute for Clinical Excellence (NICE) (see appendix 3), which was sent for comment to members of the expert advisory group for the review (see *Acknowledgements*).

The following changes were made to the methods discussed in the original protocol.

- In addition to the databases stated in the original protocol, the following databases were searched: PsycLIT, Allied and Complementary Medicine Database (AMED), Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), Health Management Information Consortium (HMIC), National Library of Medicine (NLM), Royal College of Nursing (RCN) Journals Database, HealthSTAR, Science Citation Index (SCI), Social Sciences Citation Index (SSCI) and EMBASE (see appendix 4 for details).
- At the suggestion of members of the expert advisory group, brief searches were carried out to identify any relevant high-quality evidence about the role of specialist nurses in epilepsy and Parkinson's disease (as well as diabetes, as stated in the protocol), with a view to cautious extrapolation from these disorders to MS (see chapter 4).
- Inclusion criteria, quality criteria and data extraction were undertaken by two reviewers rather than one. Any disagreements were resolved through discussion.

Electronic searches were carried out to identify evidence relating to the role of specialist nurses in MS. The sources of information used, including databases searched, are detailed in appendix 4. The inclusion criteria are those set out in the original research protocol (see appendix 3). Studies identified by the search strategy were assessed for inclusion by two reviewers at various stages. The titles and abstracts of studies were screened for inclusion by one reviewer (SdB), with decisions checked by a second reviewer (FC). The remaining papers were obtained, and the full text was examined for inclusion by both reviewers. A third reviewer (NW) also read most papers.

## Results

### Quantity and quality of research available

The searching yielded 205 references, after duplicates were excluded. All 205 titles and abstracts were scanned and assessed for inclusion; if abstracts were not available, or they did not contain sufficient detail to enable the reviewers to judge whether they met the inclusion criteria, these papers were ordered in full. In total, 31 papers were obtained as full text. These papers were all assessed for inclusion in the review by the two reviewers (SdB and FC), with 30 papers being excluded at this stage because they did not meet the inclusion criteria as stated in the protocol[10–12,17,19–44] (see appendix 5 for list of excluded studies). No randomised controlled trials (RCTs), other non-RCT experimental studies or observational studies were identified that met the inclusion criteria. Nearly all the papers contained only anecdotal accounts of the role of the MS specialist nurse and were therefore excluded from the review. The remaining paper, by Kirker and co-workers,[16] underwent quality assessment by three reviewers (see appendix 6 for the flow chart of studies identified and excluded).

In their 1995 paper, Kirker and co-workers[16] reported an evaluation of an MS liaison nurse service, which was funded from 1990 to 1992 by the MS Society of Scotland (see appendix 7 for details). The liaison nurse was based in the Medical Neurology Unit of the Western General Hospital in Edinburgh, and saw MS patients and their families at home or in the neurology ward. Subsequent contact was by telephone or in person, as necessary. The paper states that almost all newly diagnosed patients as well as any other patients who were having problems and who lived in or around Edinburgh were referred, whether they had been admitted to hospital or not. Over the 2-year period, 136 patients were referred to the nurse, 95 (70%) of whom were women and 37 (27%) of whom were newly diagnosed.

After the liaison nurse service had been running for 16 months, 82 of the patients who had been seen by the nurse were selected for interview, as were their carers. Of these, 67 patients and 51 carers, representing 71 patients (87%) in total, were subsequently interviewed and completed written questionnaires. In addition, 4 months after the end of the liaison nurse's appointment, 106 GPs were sent a postal questionnaire. Eighty of these GPs (76%) completed questionnaires about 101 of their 136 patients (74%). The liaison nurse's records were also examined retrospectively to assess the rate of referral to other services, and applications for social welfare. The rates of referral to other agencies were assessed for all patients, and also split into newly diagnosed and previously diagnosed patients.

The main results of this study are shown in *Table 2* (see appendix 7 for full details).

Although the findings from this study appear positive, there are several concerns regarding the study design. Firstly, there is a possible bias inherent within the study, because both the MS liaison nurse and the evaluation were funded by the MS Society of Scotland. In addition, the liaison nurse is also an author on the paper, and the researcher who interviewed the patients and their carers came from the same unit. An independent evaluation would have been preferable.

There is little information given in the study regarding the characteristics of the MS population from which the sample was chosen. It is unclear how many patients with MS there were in the geographical region of the study and hence what proportion of these patients was referred to the nurse. This information could be important because there may be specific characteristics of the patients who were referred that are different from those of the patients with MS who were not referred. If the patients with the highest needs were referred to the nurse, their ability to benefit would be expected to be greater than if all patients with MS were referred. This would improve the cost-effectiveness but would also reflect what would be expected in real-life situations, in which one

***TABLE 2*** *Main results from the study by Kirker and co-workers[16]*

| Study and design | Intervention | Patients | Outcome measures |
|---|---|---|---|
| Kirker *et al.*, 1995[16] | MS liaison nurse service | 136 patients with MS were referred, 82 of whom were selected for interview;<br>67 patients and 51 carers were interviewed<br>106 GPs were sent a postal questionnaire 4 months after the MS nurse's appointment ended | **Nurse's records**<br>• Rates of referral to other agencies<br>**Patient questionnaire**<br>• The written questionnaire included 15 items, each with Likert scale responses<br>• Patients were also invited to comment verbally on how they had, or had not, benefited from the liaison nurse service<br>**GP questionnaire**<br>• This questionnaire asked six questions about the GP's individual MS patients and four questions about the MS liaison nurse service in general |

**Main results (see appendix 7 for all results)**

- Overall, 21–44% of patients were referred to various therapists and 17% for respite care. Without a control group, there is no way of knowing how many patients would have been referred anyway
- Of the patients surveyed, 88% found the nurse helpful, and 39–54% reported improved life in general, coping, mood, confidence and knowledge of MS. Carers reported similar benefits
- More patients and carers found the nurse 'helpful' or 'very helpful', compared with outpatient care
- In general, patients and carers reported the greatest changes in how well they coped, their mood and confidence about the future, particularly among the newly diagnosed
- Improved mobility was reported mainly by new patients who were told about the mobility allowance or other assisted travel schemes. In patients who reported better job prospects, this gain was usually due to information about training schemes and working from home
- Of the GPs surveyed, 65% reported finding the MS nurse helpful and 23% stated that the nurse detected previously unrecognised disabilities in their patients. In addition, 23% of the GPs said that they learned something about MS from the nurse, and 40% said they would purchase the nurse's service from their budget if their practice became a fundholding practice

would expect prioritisation towards the most needy.

The most important problem with the study is that there were no controls, and it is likely that the interviews would tend to elicit a positive reaction, particularly as the nurse was still in post when the interviews were carried out, and the interviewer was not completely independent. There must be some doubt about objectivity, particularly as the study was designed to provide evidence to persuade the health board to continue funding.

## Ongoing research

We are aware of two ongoing research projects within the UK.

One project, funded jointly by South Bank University in London and the MS (Research) Charitable Trust, is a 2-year project that is due to finish in 2001. This project has two parts, the first being a comprehensive postal questionnaire of all MS specialist nurses around the country and covering issues such as employment and funding, professional development, support for the role, clinical work, the nurses' involvement in teaching, research and service development, and their role in audit and quality. The second part of the project is an in-depth case study of an MS specialist nurse(s) in West Berkshire, and will involve the nurse(s) keeping a 2-week time diary. This observational study, with no control group, is unlikely to provide good data on cost-effectiveness in terms of the impact that MS nurses have on the patients' quality of life. However, this study will provide useful data on current services and on those needs of people with MS (as perceived by both patients and professionals) that might be fulfilled by the MS nurse. These data will be used to develop the service, and there will be a before-and-after assessment.

The other project is funded by the MS Society of Great Britain and Northern Ireland, and is a multimethod evaluation of the MS Society-funded nurse posts. This study is being carried out by researchers from the School of Nursing and Midwifery at King's College, London, and is due to finish in September 2002. Up to 33 new MS nurse specialist posts are to be funded by the MS Society across the UK. The objectives of the study are to assess: (1) the current care of MS patients within host areas prior to the introduction of the MS Society-funded nurses; (2) the impact of MS Society-funded nurses on the accessibility, quality and costs of care extended to people with MS; (3) the impact of the MS Society-funded nurses on the carers of people with MS; (4) the impact of the MS Society-funded nurses on other disciplines and service providers; and (5) the impact of the MS Society-funded nurses on multidisciplinary and inter-agency working in relation to the care of people with MS.

Four sites have been selected for more detailed investigation, together with two control areas that do not have specialist MS nurses. The intervention areas are based on two specialist neurology departments, one community rehabilitation department and one general hospital. The study will allow the assessment of the effect of the nurses both by comparison of intervention and control areas, and by a before-and-after study within the intervention areas.

# Chapter 4

# Effectiveness of specialist nurses in diabetes, epilepsy and Parkinson's disease

## Methods

Because of the lack of good studies evaluating specialist nurses in MS, less extensive searches were carried out for studies evaluating the specialist nurse's role in other chronic conditions, including diabetes mellitus, epilepsy and Parkinson's disease, with a view to cautious extrapolation from those disorders to MS.

Evidence on the role of specialist nurses in diabetes was obtained by writing to the British Diabetic Association and asking them to supply any relevant papers and references. This request was thought to be the most effective way of gaining quick access to relevant papers, given the time constraints of the report. Quick electronic searches were also subsequently carried out to obtain evidence on the role of specialist nurses in both epilepsy and Parkinson's disease, as suggested by members of the advisory group. The databases searched are detailed in appendix 4.

## Results: quantity and quality of research available

The searching yielded a total of 311 references (64 for diabetes, 137 for epilepsy and 110 for Parkinson's disease). All titles and abstracts were scanned and assessed for inclusion using criteria similar to those described in chapter 3, with the result that six papers were obtained in full: three papers concerning epilepsy[45–47] and three concerning Parkinson's disease.[48–50] Unfortunately, these studies were either descriptive or largely of poor quality, and therefore did not provide us with any high-quality evidence from which to extrapolate.

One paper by Hurwitz and co-workers (1999)[49] reported the protocol of a large randomised trial evaluating community-based Parkinson's disease nurse specialists. The aims of the study were to evaluate the effectiveness of these nurses in improving the quality of life of patients with Parkinson's disease and to estimate the cost-effectiveness of this role. No results were reported, and no further details have so far been found.

# Chapter 5

## Benefits

Due to the current lack of high-quality evidence, the benefits of MS specialist nurses are impossible to quantify in terms of quality-adjusted life-years gained. However, expert opinion and anecdotal evidence suggest there may be benefits of an MS specialist nurse for both patients and carers. Given the caseload numbers per specialist nurse, it would take only a small improvement in average individual quality of life to make the provision of a specialist nurse highly cost-effective.

In the study by Kirker and co-workers,[16] the main gains reported by half of the patients and two-thirds of newly diagnosed patients were due to psychological support and reassurance that there was someone to contact in case they needed advice. There were also improvements in patients' knowledge of MS, coping, mood, confidence, life in general and family relationships.[16]

Several anecdotal studies mention the usefulness of an interdisciplinary approach to meet the neurological and rehabilitative needs of the MS patient. The MS specialist nurse could play a key role in the coordination of each discipline's contribution to the well-being of the patient.[19,22,26,39,41] Although these possible benefits cannot be quantified and at present are unsubstantiated by high-quality research, expert opinion seems to be that MS specialist nurses are valuable in the care and management of MS.

# Chapter 6

## Costs

The costs involved consist of the salary of the MS specialist nurse and additional costs, such as travel, administration, use of a telephone and computer, a pension scheme, National Insurance and study leave. MS specialist nurses are usually on NHS grade H or G, and earn £20,000–23,000 per year.[51] In London, they receive an additional London allowance and earn £23,000–26,000. However, in some areas of the UK, MS specialist nurses are on NHS grade F and earn £17,000–20,000. Taking into account the additional costs mentioned above, the MS Society allows for a total cost of the MS specialist nurse of £40,000 per year for the employer. This is an approximate estimate that allows a generous margin for all costs, including infrastructure, such as accommodation and a mobile phone/pager (Haffenden S, MS Society, London: personal communication, 2000).

One question in terms of the costs of MS specialist nurses is whether they might reduce hospital outpatient visits or GP consultations. At present, there are no good data on whether access to an MS specialist nurse will reduce costs to the NHS or social services, or whether it may actually increase costs through improved knowledge and uptake among patients and carers of possible services and benefits for which they may be eligible.

# Chapter 7

## Discussion

Most of the studies concerning the role of the MS specialist nurse are anecdotal and descriptive, and there is a paucity of research evidence in this area. Only one evaluation was identified that met the review's *a priori* inclusion criteria, namely that by Kirker and co-workers.[16] However, this study had many limitations, as described above (see *Quantity and quality of research available*). The currently ongoing study funded by the MS Society of Great Britain and Northern Ireland will help plug the research gap.

An MS specialist nurse can offer many possible benefits to MS patients and their carers, including increased knowledge of MS, increased coping and confidence, and improved awareness of and access to other services and benefits.

In the absence of high-grade research, we routinely take account of expert opinion. Those neurologists whom we have consulted believe strongly in the value of specialist MS nurses. Comments from people with MS indicate that they greatly value support from MS nurses. These opinions, based on practical experience, provide the best evidence currently available.

### Factors relevant to NHS policy

There is an uneven distribution of MS nurses around the country, with patients in some areas having little or no access to an MS specialist nurse. It is also clear that the present nurses are funded by a variety of sources (e.g. the NHS, pharmaceutical industry and charities, including the MS Society). The MS nurses are generally based in specialist neurological services, which may contribute to the geographical inequity. As the MS Society[52] points out in a recent newsletter:

> "...the vast majority of people with MS live at home, relying on their GP and district nurse for care. It is vital therefore that MS nurses follow patients through into the community, and provide specialist advice to GPs and district nurse colleagues."

### Conclusion

Our conclusion is that MS specialist nurses are probably very helpful to patients, but this conclusion is based on anecdote and opinion, in the absence of good data. Further research is needed before any firm recommendation on the value of specialist nurses in MS, relative to other possible developments, can be made.

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# Appendix 1

## Questionnaire

1. Are you currently working as an MS specialist nurse? Yes ☐ No ☐

2. Roughly how many MS patients do you look after? ☐

3. Roughly how many MS patients do you have contact with each week? ☐

4. Where does the funding for your post come from? ..........................................................................................

5. Roughly how much of your time do you spend on the following activities? *(please give an approximate % of time spent)* %

   - Providing information/education/advice to newly diagnosed MS patients and/or their family/carers ☐
   - Providing psychological support/counselling to newly diagnosed MS patients and/or their family/carers ☐
   - Providing ongoing information/education/advice to MS patients and/or their family/carers ☐
   - Providing ongoing psychological support/counselling to MS patients and/or their family/carers ☐
   - Providing care or psychological support when MS patients have relapses ☐
   - Care management (e.g. liaising with/referral to other professionals) ☐
   - Providing aids for activities of daily living (or liaising with other professionals to supply such aids) ☐
   - Advising on problems such as incontinence, pain, etc. (e.g. how to handle such problems at home) ☐
   - Providing community follow-up visits ☐
   - Providing follow-up appointments in outpatient clinics ☐
   - Providing training/education to other healthcare professionals ☐
   - Research ☐
   - Audit ☐
   - Other *(please state)* .............................................................................................................................. ☐

6. If you had 20% more time available to you, how would you use this extra time?
   ..........................................................................................................................................................................

7. If you had 50% more time available to you, how would you use this extra time?
   ..........................................................................................................................................................................

8. If you had 20% less time available to you, what activities would you reduce/not perform at all?
   ..........................................................................................................................................................................

9. Do you have any other comments you wish to make? *(please write down below, and continue on reverse if necessary)*
   ..........................................................................................................................................................................

# Appendix 2

## Summary of questionnaire responses

The activities listed in the questionnaire and the average proportion of time MS nurses spent on them (% of total time) were reported as follows:

| | |
|---|---|
| • providing ongoing information/education/advice to MS patients and/or their family/carers | 15% |
| • providing community follow-up visits | 11% |
| • providing ongoing psychological support/counselling to MS patients and/or their family/carers | 10% |
| • providing information/education/advice to newly diagnosed MS patients and/or their family/carers | 9% |
| • providing care or psychological support when MS patients have relapses | 9% |
| • care management | 9% |
| • providing psychological support/counselling to newly diagnosed MS patients and/or their family/carers | 8% |
| • advising on problems such as incontinence, pain, etc. | 8% |
| • providing follow-up appointments in outpatient clinics | 8% |
| • providing training/education to other healthcare professionals | 5% |
| • providing aids for activities of daily living | 3% |
| • research | 2% |
| • audit | 2% |
| • other | 2% |

If the MS nurses had 20% more time, they reported that they would dedicate it to the following activities:

- providing a quality service
- doing research
- providing proactive education to health carers/professionals
- setting up a counselling group for newly diagnosed patients
- catching up with paperwork and filing
- ensuring more structured long-term patient follow-up and catching up with ongoing projects
- seeing more patients per week
- service development and teaching
- providing support to people on various treatment regimens
- spending time finding patients with MS who do not access our service.

If the MS nurses had 50% more time, they would dedicate it to the following activities:

- providing quality service
- extending their own role
- peer support and educational programmes for carers/professionals
- setting up young carers facilities, drop-in facility, more group activities
- more new services for newly diagnosed groups
- completing audit of service and developing research proposals with support from university staff
- ensuring more structured patient follow-up and catching up with ongoing projects
- seeing more patients and increasing personal study time
- commencing a continence clinic
- completing a database of information sources on computer
- developing services available locally into a wider area
- setting up a clinic to cut down on travel
- providing a better support structure for people with MS of all types and at all stages
- auditing and researching how to improve the service.

If the nurses had 20% less time available, they would:

- reduce their own professional development
- cut down on hospital activities
- reduce the number of community visits
- reduce time spent on paperwork
- reduce training and availability
- stop attending neurologists' clinics
- reduce time spent teaching professionals and carers
- reduce time spent with the patient
- not do research
- expect waiting times to lengthen
- reduce home visits.

# Appendix 3

# Methods of the review: original protocol, November 1999

## Research question

- The aim of the review was to assess the effectiveness and cost-effectiveness of specialist nurses in MS.
- The research question originally stated in the correspondence from NCCHTA (National Coordinating Centre for Health Technology Assessment) was that of "Care packages/ Specialist nurses for MS". The Wessex review team were subsequently informed that they should scope the research question.
- After preliminary searching on MEDLINE and CINAHL, the research question was changed to "The role of specialist nurses in MS". The justification for this is that it appears that, although the role of specialist nurses in MS will include care management, they are also likely to have other roles/functions in addition to care management, for example, the provision of information/ support at diagnosis and during relapses.
- It is acknowledged that focusing on the role of the MS specialist nurse may ignore the potential roles of other professionals acting as care managers for patients with MS. For example, other healthcare professionals such as physiotherapists may occasionally fulfil the role of care manager for patients with MS. Different professions may lead care at different stages of the disease. However, within the timescale of this review, it was felt that we should focus specifically on the role of the MS specialist nurse.
- The review will be undertaken as systematically as time allows, following the general principles outlined in NHS CRD (Centre for Reviews and Dissemination) Report 4.
- Based on initial searches, we do not anticipate finding sufficient data to support a meta-analysis or cost-effectiveness analysis.

## Inclusion criteria

### Interventions

- The intervention is the specialist nurse for patients with MS.
- The role of the MS specialist nurse will include care management.

### Participants

- People diagnosed with MS.

### Study designs

- We will search for and include the following study designs, in descending order, selecting the most rigorous study designs available:
  a. systematic reviews and randomised controlled trials (RCTs)
  b. other (non-RCT) experimental study designs
  c. observational studies, such as before and after studies of the effect on quality of life or other patient outcomes
  d. qualitative studies, including surveys of patient's views of benefits.
- It appears from the preliminary literature search unlikely that study designs such as RCTs or other experimental designs will have been used to evaluate the role of the MS specialist nurse. Therefore, qualitative study designs will be included if appropriate.

### Types of outcome measure

- Patient-related outcomes will be the primary outcome measures sought, for example, symptom management, quality of life and quality of care.

### Search strategy

- Electronic databases that will be searched include: The Cochrane Library (includes CDSR [Cochrane Database of Systematic Reviews], DARE [Database of Abstracts of Reviews of Effectiveness] and CCTR [Cochrane Controlled Trials Register]), MEDLINE, PreMEDLINE, CINAHL, NHS Economic Evaluation Database (NHS EED) and the National Research Register (NRR). These will be searched for the period 1982 to 1999 and will be limited to English language studies.
- Bibliographies of related papers will be assessed for relevant studies.

### Quality criteria

- Included studies will be assessed using the critical appraisal criteria outlined in the Wessex Institute for Health Research and Development Rapid Reviews Team Guidelines.

## Review methods

- Inclusion criteria will be applied by one reviewer.
- Quality criteria (critical appraisal) will be agreed in advance, revised if necessary and applied by one reviewer.
- Data extraction will be undertaken by one reviewer.
- If, as anticipated, there is little published literature evaluating the role of the MS specialist nurse, it may be possible to look briefly at published evidence concerning specialist nurses in diabetes (who support and monitor patients with another long-term disabling disease with neurological problems), with the aim of drawing parallels with MS specialist nurses.
- Due to the anticipated small amount of published literature in this field, we will (if adequate information cannot be obtained from other sources) undertake a very brief questionnaire survey of a small number of specialist MS nurses. The objective of the questionnaire is to gain an impression of the MS specialist nurse's role.
- If it is necessary, the questionnaire survey will be undertaken as follows:
  a. A list of MS nurses will be obtained from the MS Society.
  b. Telephone conversations will be carried out with one or two specialist MS nurses to obtain information on their role, to aid with questionnaire design.
  c. Development of a very brief questionnaire (one side of A4), to be sent to the MS nurses (50 MS nurses maximum), including asking about number of patients looked after, contacts per week, etc.
  d. Two weeks to be allowed for replies.
  e. Non-responders will not be contacted with reminders due to the short timescale of the review.
  f. Detailed computerised analysis will not be necessary due to the simplicity of the questionnaire.

# Appendix 4

## Search strategy

### Specialist nurses in MS

The following methods were used to identify information and evidence relating to the role of the specialist nurse in MS.

| **Databases searched**[†] | **Issue or dates** |
|---|---|
| MEDLINE | 1985–1999 (October) |
| PreMEDLINE | Searched on 8 December 1999 |
| The Cochrane Library | Searched on 1 December 1999 |
| CINAHL | 1982–1999 (July) |
| PsycLIT | 1994–1999 (December) |
| AMED | 1985–1998 (December) |
| ASSIA | 1986–1999 |
| BNI | 1980–1999 (August) |
| HMIC | Searched on 3 December 1999 |
| NLM | Searched on 3 December 1999 |
| RCN Journals Database | 1985–1996 |
| HealthSTAR | 1975–1999 |
| SCI/SSCI, via Bath Information and Data Services (BIDS) | Searched on 3 December 1999 |
| EMBASE | 1980–1999 (August) |
| NHS EED | Searched on 1 December 1999 |
| NRR | Searched on 1 December 1999 |

- Medical Subject Headings (MeSH) terms used: ‘Multiple sclerosis’ under the ‘Nursing’ subheading
- Free text search: ‘Multiple sclerosis near/and nurs*’

Additional sources included:

- reference lists of relevant papers
- personal communication with experts.

### Specialist nurses in epilepsy and Parkinson’s disease

The following methods were used to identify information and evidence relating to the role of the specialist nurse in epilepsy and Parkinson’s disease.

| **Databases searched**[†] | **Issue or dates** |
|---|---|
| PsycLIT | 1994–1999 (December) |
| EMBASE | 1999 (January)–1999 (June) |
| BNI | 1986–1999 (September) |
| CINAHL | 1997–1999 (November) |
| MEDLINE Express | 1999 (January)–1999 (October) |

- MeSH terms used: ‘Epilepsy’ under the ‘Nursing’ subheading; ‘Parkinson-Disease’ under the ‘Nursing’ subheading
- Free text search: ‘Epilepsy near nurs*’ ; ‘Parkinson* disease near nurs*’

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[†] English language restrictions were applied

# Appendix 5

## Excluded studies

Aronson KJ, Cleghorn G, Goldenberg E. Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disabil Rehabil* 1996;**18**:354–61.

Banks SA. Consider the mind as well as the body. Nursing care and support in multiple sclerosis. *Prof Nurse* 1990;**6**:9,12–16.

Barnes MP. Treating and nursing patients with multiple sclerosis. *Nurs Stand* 1997;**11**:42–4.

Burks J. Multiple sclerosis care: an integrated disease-management model. *J Spinal Cord Med* 1998;**21**:113–16.

Campion K. Disease management. Living with multiple sclerosis. *Community Nurse* 1996;**2**:27–9.

Campion K. Meeting multiple needs...multiple sclerosis. *Nurs Times* 1996;**92**:28–30.

Campion K. Multiple sclerosis. *Prof Nurse* 1997; **13**:169–72.

Campion K. Multiple sclerosis. Professional issues. *Nurs Times* 1997;**93**:57–60.

Campion K, Cole A. Multiple sclerosis. The role of the nurse...part 2. *Nurs Times* 1997;**93**:59–62.

Chuk PK-C. Clinical nurse specialists and quality patient care. *J Adv Nurs* 1997;**26**:501–6.

Crawford M. Multiple sclerosis: the role of the nurse. *Pract Nurs* 1995;**6**:13–15.

Freeman J, Johnson J, Rollinson S, Thompson A, Hatch J. Standards of healthcare for people with MS. London: Multiple Sclerosis Society of Great Britain and Northern Ireland; 1997.

Gould MT. Nursing diagnoses concurrent with multiple sclerosis. *J Neurosurg Nurs* 1983;**15**:339–45.

Graff WL, Bensussen WW, Cody E, Williamson J. Population management in an HMO: new roles for nursing. *Public Health Nurs* 1995;**12**:213–21.

Grudzinski AN, Hakim Z, Cox ER, Bootman JL. The economics of multiple sclerosis. Distribution of costs and relationship to disease severity. *Pharmacoeconomics* 1999;**15**:229–40.

Halper J. The nurse case manager in multiple sclerosis. *J Care Manag* 1998;**4**:12–25.

Johnson J. What can specialist nurses offer in caring for people with multiple sclerosis? In: Thompson A, Polman C, Hohlfeld R, editors. Multiple sclerosis: clinical challenges and controversies. London: Martin Dunitz; 1997. p. 335–43.

Knight D. Professional issues: taking a close look at the work of a multiple sclerosis nurse. *Community Nurse* 1998;**4**:43.

Meyer C, Moran E, Luoto E, Conway K. The role of the MS specialist nurse. *Int MS J* 1998;**5**:24–9.

Murphy N, Confavreux C, Haas J, Konig N, Roullet E, Sailer M, *et al.* Economic evaluation of multiple sclerosis in the UK, Germany and France. *Pharmacoeconomics* 1998;**13**:607–22.

Nolan M, Nolan J. Rehabilitation in multiple sclerosis: the potential nursing contribution. *Br J Nurs* 1997;**6**:1292–309.

Pinn S. Multiple sclerosis management. *Pract Nurse* 1997;**14**:115–18.

Sitzia J, Haddrell V, Rice OM. Evaluation of a nurse-led multidisciplinary neurological rehabilitation programme using the Nottingham Health Profile. *Clin Rehabil* 1998;**12**:389–94.

Sparrow S. The nurse's role in the care of people with MS. *Nurs Times* 1998;**94**:54–5.

Thompson SB. Providing a neuropsychology service for people with multiple sclerosis in an interdisciplinary rehabilitation unit. *Disabil Rehabil* 1996;**18**:348–53.

Wahlquist GI. Impact of a nurse managed clinic in multiple sclerosis. *J Neurosurg Nurs* 1984;**16**:193–6.

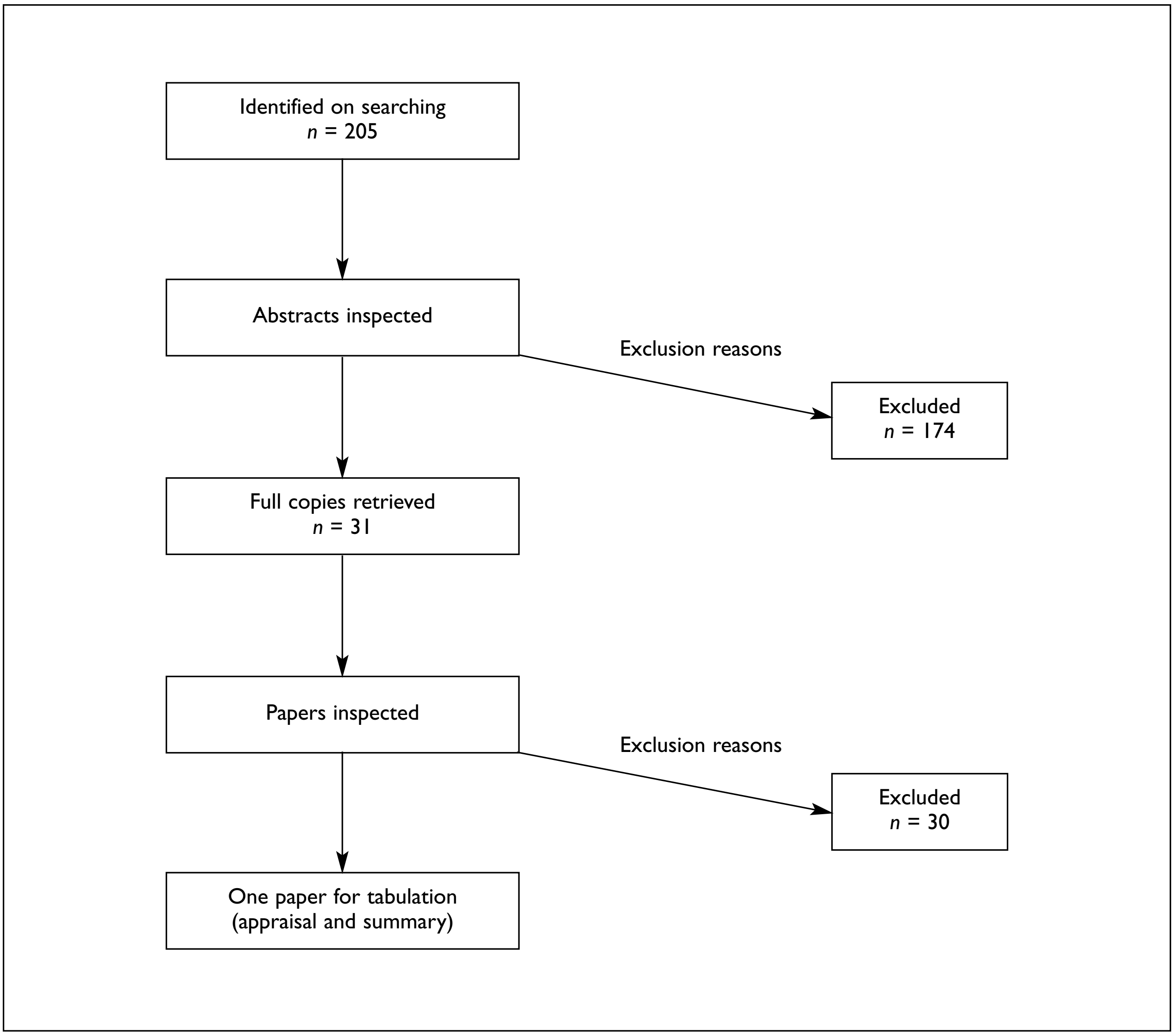
Wilson R. The Multiple Sclerosis Partnership Programme. *Int MS J* 1998;**5**:30–4.

Wilson-Barnett J, Beech S. Evaluating the clinical nurse specialist. A review. *Int J Nurs Stud* 1994;**31**:561–71.

Winters S, Jackson P, Sims K, Magilvy J. A nurse-managed multiple sclerosis clinic: improved quality of life for persons with MS. *Rehabil Nurs* 1989;**14**:13–16.

# Appendix 6

## Flow chart of identification and inclusion of studies



# Appendix 7

## Tabulation of evidence

| Study and design | Intervention | Patients | Outcome measures |
|---|---|---|---|
| Kirker *et al.*, 1995[16] (UK)<br>An evaluation study | MS liaison nurse service (funded from 1 May 1990 to 30 April 1992). The liaison nurse was based in the Medical Neurology Unit, Western General Hospital, Edinburgh, UK | In total, 136 patients with MS were referred to the nurse over the 2-year period. Of these, 70% (*n* = 95) were women, and 27% (*n* = 37) were newly diagnosed<br>After the project had been running for 16 months, all patients that had been seen by the nurse (*n* = 82) were selected for interview, as were their carers. Subsequently, 67 patients and 51 carers, representing 71 patients (87% of those seen) in total, were interviewed and completed written questionnaires. Of these patients, 62% (*n* = 44) were women, and 28% (*n* = 20) were newly diagnosed<br>Four months after the end of the liaison nurse's appointment, 106 GPs were sent a postal questionnaire. Of these GPs, 80 (76%) completed questionnaires about 101 (74%) of their 136 patients | **Nurse's records**<br>• The liaison nurse's records were examined retrospectively to assess the rates of referral to other services, and applications for social welfare<br>• The rates of referrals to other agencies were assessed for all patients, and also split into the rates for patients who were newly diagnosed compared with previously diagnosed<br>**Patient questionnaire**<br>• The written questionnaire included 15 items, each with five Likert scale responses: whether neurology outpatient or inpatient care or the liaison nurse had been helpful, amount of information about MS received in hospital, whether the nurse had influenced their mood, confidence about the future, knowledge of MS, life in general, relationship with the carer (or patient), mobility, patient's dependence on others, job prospects, how well they were coping, and the frequency of visits to the GP or hospital<br>• Patients were also invited to comment verbally on how they had, or had not, benefited from the liaison nurse<br>**GP questionnaire**<br>• The GP's postal questionnaire asked six questions about their individual MS patients: whether the nurse had detected any previously unrecognised disabilities/problems, whether the nurse had affected the GP's relationship with the patient and family, whether the nurse had affected the GP's workload, whether the GP had found the service helpful, whether the nurse had reduced the need for hospital referral and whether communication with the liaison nurse had been adequate<br>• It also asked four questions about the service in general: whether this service would be useful for newly diagnosed patients, whether this service would be useful for disabled patients, whether the GP had learned anything about managing MS from the nurse and whether the GP would purchase this service if his/her practice became a fundholding practice |

*continued*

*contd*

***Results***

**Assessment of the workload of the nurse**

- For all patients (*n* = 71), the median number of personal or telephone contacts per patient was eight. For the newly diagnosed patients, the median number of contacts was seven, and for previously diagnosed patients, it was eight
- Referrals to other agencies for all patients (*n* = 71), newly diagnosed patients (*n* = 20) and previously diagnosed patients (*n* = 51), respectively, were as follows:
  - physiotherapy: 25% (*n* = 18), 25% (*n* = 5), 25% (*n* = 13)
  - occupational therapy: 44% (*n* = 31), 30% (*n* = 6), 49% (*n* = 25)
  - social services: 41% (*n* = 29), 30% (*n* = 6), 47% (*n* = 24)
  - incontinence clinic: 21% (*n* = 15), 15% (*n* = 3), 24% (*n* = 12)
  - psychiatry: 18% (*n* = 13), 20% (*n* = 4), 18% (*n* = 9)
  - respite care: 17% (*n* = 12), 0% (*n* = 0), 24% (*n* = 12)
  - sexual dysfunction clinic: 4% (*n* = 3), 10% (*n* = 2), 2% (*n* = 1)
  - wheelchair assessment: 17% (*n* = 12), 5% (*n* = 1), 22% (*n* = 11)
- The average cost per patient contact (based on the total number of contacts and the nurse's salary and travelling, telephone and other direct expenses over 2 years) was about £30. The major additional costs would have been social welfare benefits, appliances, referral to other therapists and inpatient respite care

**Patient's and carer's questionnaires**

- Results for **all** patients (*n* = 67) and **all** carers (*n* = 51), respectively, are shown (intermediate responses not reported):
  - liaison nurse: 88% (*n* = 59) and 88% (*n* = 45) found the liaison nurse 'very helpful' or 'helpful', while 4% (*n* = 3) and 2% (*n* = 1) found the nurse 'very unhelpful' or 'unhelpful'
  - neurology outpatient care: 69% (*n* = 46) and 55% (*n* = 28) found neurology outpatient care 'very helpful' or 'helpful', while 9% (*n* = 6) and 8% (*n* = 4) found it 'very unhelpful' or 'unhelpful'
  - neurology inpatient care: 58% (*n* = 39) and 61% (*n* = 31) found neurology inpatient care 'very helpful' or 'helpful', while 9% (*n* = 6) and 4% (*n* = 2) found it 'very unhelpful' or 'unhelpful'
  - information at hospital: information given at the hospital was reported to be 'enough' for 37% (*n* = 25) and 37% (*n* = 19), and 'too little or none' for 60% (*n* = 40) and 59% (*n* = 30)
  - MS knowledge: 54% (*n* = 36) and 55% (*n* = 28) reported that their knowledge of MS was 'much better' or 'better', compared with 4% (*n* = 3) and 2% (*n* = 1) who reported that it was 'much worse' or 'worse'
  - coping: 51% (*n* = 34) and 49% (*n* = 25) reported that they were coping 'much better' or 'better', while 6% (*n* = 4) and 4% (*n* = 2) said they were coping 'much worse' or 'worse'
  - mood: 42% (*n* = 28) and 37% (*n* = 19) said that their mood was 'much better' or 'better', while 6% (*n* = 4) and 16% (*n* = 8) said that it was 'much worse' or 'worse'
  - confidence: 40% (*n* = 27) and 33% (*n* = 17) said that their confidence was 'much better' or 'better', while 4% (*n* = 3) and 6% (*n* = 3) said that it was 'much worse' or 'worse'
  - life in general: 39% (*n* = 26) and 43% (*n* = 22) said that their life in general was 'much better' or 'better', while 6% (*n* = 4) and 6% (*n* = 3) said that it was 'much worse' or 'worse'
  - family relationships: 27% (*n* = 18) and 29% (*n* = 15) said that their family relationships were 'much better' or 'better', while 3% (*n* = 2) and 4% (*n* = 2) said that they were 'much worse' or 'worse'
  - patient's dependence: 19% (*n* = 13) and 18% (*n* = 9) said that the patient's dependence had 'reduced', while 22% (*n* = 15) and 20% (*n* = 10) said that it had 'increased'
  - GP visits: 24% (*n* = 16) and 12% (*n* = 6) said that their GP visits had 'reduced', while 7% (*n* = 5) and 12% (*n* = 6) said that they had 'increased'
  - hospital visits: 24% (*n* = 16) and 10% (*n* = 5) said that their hospital visits had 'reduced', while 6% (*n* = 4) and 6% (*n* = 3) said that they had 'increased'

**GP's questionnaires**

- In total, 101 questionnaires were completed by the GPs, who answered questions about their **individual** patients with MS:
  - 65% (*n* = 66) stated that the nurse had been helpful
  - 23% (*n* = 23) stated that the nurse had detected previously unrecognised disabilities
  - 34% (*n* = 34) stated that the GP's workload had been reduced
  - 22% (*n* = 22) stated that the GP's relationship with the patient and family had been improved
  - 16% (*n* = 16) stated that the number of referrals to hospital had reduced
  - 59% (*n* = 60) stated that the communication between the GP and liaison nurse was adequate

- GPs answered questions about the service in general:
  - 74% (*n* = 59) said that they thought the service would be useful for newly diagnosed patients
  - 79% (*n* = 63) said that they thought the service would be useful for disabled patients
  - 23% (*n* = 18) said that they had learned something about managing MS from the nurse
  - 40% (*n* = 32) said that they would purchase the service if their practice became a fundholding practice

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***Comments***

- There is a possible bias inherent in the study because the liaison nurse and the evaluation were both funded by the MS Society of Scotland, and the study appears to have been done in order to gather evidence with which to convince the health board to continue the funding. In addition, the researcher who interviewed the MS patients and their carers had either met or been involved in the care of some of these patients (the article states fewer than 10%). The authors state that "while a completely independent assessor would have been methodologically preferable, bias due to this is unlikely to have affected the results of the questionnaires or content of the interviews." This view is perhaps questionable, and an independent evaluation would have been preferable
- There is little information given in the study about the characteristics of the MS population from which the sample was chosen. It is unclear how many MS patients there were in the geographical region of the study and hence what proportion of these were referred to the nurse. This information could be important because there may be specific characteristics about the patients who were referred that are different from those of the MS patients who were not referred. If the patients with the highest needs were referred to the nurse, then it is questionable whether the service would still be as effective when extrapolated to all MS patients
- Of those MS patients who were referred to the nurse, only some of them were actually seen by her and hence eligible for interview. Again, this raises questions about the characteristics of this population of MS patients, compared with those who were referred to the nurse but not seen by her, because only limited information was given in the study
- It is unclear how the sample of GPs who were sent questionnaires was chosen
- There were no controls in the study, and it is likely that the interviews would tend to elicit a positive reaction, particularly as the nurse was still in post when the interviews were carried out
- It is unclear whether the results are transferable to other settings or other groups of MS patients

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## Feedback

The HTA programme and the authors would like to know your views about this report.

The Correspondence Page on the HTA website (http://www.ncchta.org) is a convenient way to publish your comments. If you prefer, you can send your comments to the address below, telling us whether you would like us to transfer them to the website.

***We look forward to hearing from you.***

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