Final Report for the Foundation of Nursing Studies

Developing a Community Link Nurse Role for Parkinson’s Disease

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Parkinson’s disease, Community Link Nurse, skill mix, work based learning

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Location of Project:
Isle of Wight NHS Primary Care Trust

Summary
This project explored the use of skill mix to increase the service hours provided by the Parkinson’s Disease Nurse Specialist through developing a community link nurse role. Following a survey of service users, an education programme was developed for the Parkinson’s Disease Link Nurse and achieved through work based learning. Although developing the new role was successful, inadequate service hours remained a problem. Therefore a new service business plan was submitted to the Primary Care Trust using some of the evidence collected through this project.

Background
Parkinson’s disease is the most prevalent neurological degenerative disease after Alzheimer’s disease. It is therefore a common, age related, disabling neurodegenerative disorder. Parkinson’s disease has high cost implications not only in terms of health and social care but quality of life issues for the individual, their families and carers (Thomas, MacMahon and Maguire, 2006).

In February 2002, a full time Parkinson’s Disease Nurse Specialist was employed through an initial 2 year pump priming post funded by the Parkinson’s Disease Society. The aim of this post was to develop a patient centred, community based pro-active service for patients and carers on the Isle of Wight. Pivotal to the role of the Parkinson’s Disease Nurse Specialist is the provision of timely multidisciplinary intervention and medicines management to minimise disability and maximise benefits of medications. Direct access and open referral to the Parkinson’s Disease Nurse Service also provides a direct port of call for patients and carers needing information, education and support throughout the disease process.

Feedback from a satisfaction survey of service users suggested that patients and carers considered the Parkinson’s Disease Nurse service to be very valuable and a sustained reduction in hospital admissions was also identified. However, over 500 patients were referred to the service within the first two years and the demands on one nurse became too high to manage within the existing level of resources. A need for service redesign was identified but this had to be done with existing resources. A review of the caseload was therefore undertaken. This identified that the needs of patients and carers was varied and so it was proposed that the provision of a skill mixed service could enable increased service provision.
**Project aim**
To develop a community link nurse role within existing resources by exchanging 7.5 hours at band 7 for 10 hours at band 5. This was initially offered as a secondment opportunity of an existing Community Nurse to develop the role within a work based learning environment.

**Project outline**
Following recruitment of the Community Link Nurse a service users survey was developed to identify which services provided by the Parkinson’s Disease Nurse Specialist were considered useful and what changes could be made. The outcomes of the survey were used to structure a work based learning programme, which was individually tailored to meet the needs of both identified service requirements and the training needs of the Community Link Nurse. Evaluation was an ongoing process which included a process of reflective practice.

**Initial survey**
An initial survey was carried out which included members of the local Parkinson’s Disease Society and the Multidisciplinary Team. 63 people (31 members of the Multidisciplinary Team and 32 members of the Parkinson’s Disease Support Group) were asked to complete a simple Yes/No questionnaire (see Box 1) related to the provision and development of the Parkinson’s Disease Nurse Service provided on the Isle of Wight.

Questionnaires were disturbed during two separate meetings held to discuss the Community Link Nurse proposal. One meeting was for patients and carers (Parkinson’s Disease Support Group) the other for Multidisciplinary Health Care professionals. All who attended completed a questionnaire.

100% of respondents stated they wanted the service to continue and supported the provision of part-time cover by a Community Link Nurse.

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Box 1. Survey questions

Which of the following options do you feel would be a useful service development?

1. Dedicated telephone advice service for patients, carers and health care professionals. Time 8.30-10.30 am.
2. Skill mix to maintain and manage home visits service with more flexibility.
3. Education and training to promote self help and independence.
4. Provision of part-time cover by the link nurse when the Parkinson’s Disease Nurse Specialist is on leave.
5. To maintain provision of Parkinson’s service.
Figures 1 and 2 below show the responses to the questionnaire.

**Figure 1. Parkinson’s Disease Society Support Group Responses**

![Bar chart showing responses to questions 1 to 5.]

(1 respondent didn’t reply to questions 3 and 4.)

**Figure 2. Multi Disciplinary Team Responses**

![Bar chart showing responses to questions 1 to 5.]

The following comments were also offered by respondents in the space provided.

- Keep up the good work Sue
- This is all essential services
- Advice line available through HQ?
- These are all very important facilities
- Very valuable services
- I agree empowering patients helps them to self manage and requires less support
• Needed for advice as two weeks waiting for patients is not satisfactory for patients.
• Email communication better for health professionals
• Education for health care workers
• Excellent service – glad to hear you are expanding the service.
• An invaluable service which needs all the help and finance it can get.
• Very reliable service that should be allowed to be developed to support patients in the community and prevent hospital admissions
• From a domiciliary physio point of view the service provided by Sue has been very helpful to gain more information and support, sharing information and having a connection to report any problems.
• Excellent service - which must continue.
• A highly valuable service. Thank you
• To maintain service- a must

The outcomes of the survey enabled the Community Link Nurse role to be structured and provide a framework for work based learning.

**Developing the role of the Parkinson’s Disease Community Link Nurse**

The role of the Community Link Nurse was identified following a caseload review by the Parkinson’s Disease Nurse Specialist. A review of skills required to meet the needs of the caseload identified that approximately 20% of the workload could be completed by a band 5 community nurse. The nurse would maintain routine reviews, support visits under the supervision of the Parkinson’s Disease Nurse Specialist. The Community Link Nurse would also maintain a limited supportive service while the Parkinson’s Disease Nurse Specialist was on leave.

Although only one nurse applied for the post, she showed a keenness to learn more about long term conditions and felt the post would enhance her role as a Community Nurse. She therefore combined the 10hrs Community Link Nurse role with her existing part time Community Nurse hours.

Maintenance of the Parkinson’s Disease Service was achieved while the Community Link Nurse role was being implemented, however, this was difficult at times as the hours of the Parkinson’s Disease Nurse Specialist were being reduced. Therefore, when the Link Nurse was on study leave or annual leave less service hours were available. This was addressed by the provision of increased hours on an ad hoc basis which had to be agreed by the line manager.

**Work based learning**

Learning in the workplace often occurs unconsciously but can be structured or planned to contribute towards academic awards or portfolios to provide evidence of learning outcomes and achievements.
Work based learning is about learning:

- While at/in your place of work
  
  The Community Link Nurse spent time shadowing the Parkinson’s Disease Nurse Specialist and other Specialist Nurses in the South Coast region to compare practice and develop skills.

- Through work – while you are working
  
  Time was spent in the Neurology clinics to observe the neurologists in diagnosis of Parkinson’s Disease and reviews of patients. This also provided peer support and a greater understanding of local service delivery.

- For work – doing new or existing things better
  
  The Community Link Nurse was involved in the delivery of the initial survey and the development of the work base learning programme. This was to ensure her preferred learning style was met and she had a clear understanding of her role in meeting service requirements.

- From the experience of work, and reflecting on that experience
  
  An identified caseload was established for the Community Link Nurse to review and develop her practice through. A process of reflection, joint assessment and peer review also was encouraged.

Further learning took place in more formal settings and through distance learning and to support the development of the Community Link Nurse role, a structured educational programme was developed which included:

- Working through a Competences Framework based on ‘Competencies: An Integrated Career and Competency Framework for Nurses Working in Parkinson’s Disease Management’, a joint publication devised by The Royal College of Nursing Neuroscience Forum, the Parkinson’s Disease Society and Parkinson’s Disease Nurse Specialist Association (2005)

- Distance Learning – undertaking a professional diploma in Parkinson’s Disease co-ordinated by Leeds Metropolitan University, comprising of 3 modules focusing on the diagnosis, management and psycho social aspects of Parkinson’s Disease undertaken over 18 months

- Attendance of training events – numerous study days including, Southern PD forum, International non-motor group

- Peer review – using the opportunity to work with existing and experienced Parkinson’s Disease Nurses in the South of England individually and by attending and participating in bi-monthly Parkinson’s Disease Nurse Specialist clinical supervision and support meetings at the south coast Parkinson’s Disease nurse forum

Work based learning opportunities were used to create a framework for learning to aid development of the Community Link Nurse. Work based learning supported the identified learning needs within the Community Link Nurse role enabling the development of new skills and competencies while introduce evaluation and change within the service.
The learning experiences over the past 12 months have supported development of the Community Link Nurse enabling consolidation of skills developed in practice. It has also enabled an opportunity for the Parkinson’s Disease Nurse Specialist to develop new skills and reflect on her practice through peer review. Although time is always an issue, work based learning has given the opportunity to be flexible and novel in our approach to learning.

Work based learning enabled maintenance of service provided to the Parkinson’s population whilst integrating the Parkinson’s Link Nurse role. We were then able to explore the qualitative value of the Parkinson’s Link Nurse role from a service user’s perspective.

**Evaluating the Community Link Nurse role**

A simple Yes/No questionnaire (see Box 2) relating to the quality of visits from the Parkinson’s Disease Community Link Nurse was created. This was given to a sample group of 6 patients. (20% of the Community Link Nurses caseload). Questionnaires were given out by the Parkinson’s Disease society support worker during a monthly support group meeting and collected on the same day. Patients were randomly selected as the Community Link Nurse did not know how many or her caseload would attend the support group meeting.

**Box 2. Questions asked to evaluate patient satisfaction of the service provided by the Parkinson’s Disease Link Nurse**

1. Do you see the Link Nurse regularly?
2. Is the Link Nurse able to answer any questions you may have?
3. Are you able to answer any questions the nurse may ask you?
4. Have you had any hospital admissions since seeing the Link Nurse?
5. If so was this related to your Parkinson’s Disease?
6. Does the Link Nurse refer you to other specialists when the need arises?
7. Have you been given an information leaflet about the role of the Parkinson’s Disease Nurse?
8. If you have been given this leaflet, did you find it helpful?
9. Overall how would you rate the care you receive from the Link Nurse?
10. Any other comments

Box 3 below provides the service users’ responses to questions 1-8.
Question 9 provided tick box choices for service users of very poor, poor, fair, good, very good and excellent. 2 service users responded ‘very good’ and 4 responded ‘excellent’.

Question 10 asked service users to provide any other comments. The following comments were offered:

- Sarah, Parkinson’s Nurse has been very supportive at a difficult time
- Very helpful and supportive and a quick response
- Always a quick and informed response, friendly and efficient service
- Reassuring to know PDNS is there to help and give advice and makes quick contact to assess problem

Although only a limited number of service users were involved in the evaluation, the feedback suggests that the service provided by the Parkinson’s Link nurse had proved to be beneficial to the patient group. The quality of service provided was reported to be very good by 44% of respondents and excellent by 66% of respondents. Only one respondent had a hospital admission related to their Parkinson’s disease over an 18 month period.

Reflection
Reflective practice involves evaluating and reflecting on the result of practice before engaging in practice again. This must also function at an organisational level, making managers aware of factors which impinge on practice (Mulhall and May, 1999). Within this project practice has been examined to enable dialog between management, commissioner, service users and service providers to inform the organisation of service needs and options.

Key reflections have identified that developing the role of the Community Link Nurse has had many advantages such as peer support, increased flexibility and service provision during annual leave, study leave or sick leave. It has also enabled sharing of knowledge, increased specialist training, awareness in Parkinson’s disease and provided a means for succession planning. However, the development process has
also highlighted that the number of service hours provided is not enough to maintain service needs. Although some time was supported through paid excess hours, many were provided through good will and therefore were not formalised within the initial service plan. Through the regional Parkinson’s Disease Nurse Specialist Support group, it has been identified that many nurses are working beyond their contracted hours to meet service needs. It is therefore important that nurses make a clear log of activities and hours spent in providing services to patients with long term conditions such as Parkinson’s disease to ensure adequate service hours are provided to meet the ongoing needs of patients and carers.

**Outcome**

This project has involved the integration of new knowledge and skills gained and the direct application of findings. This has involved a process of initiating an idea and a general objective, followed by a process of planning, acting, observing and reflecting.

Working within the area of service development for people with Parkinson’s disease over the past 6 years has helped to make sense of the problems in service delivery and promoting initiatives to sustain or modify the service provided. This report reflects service users satisfaction with the support available from the Parkinson’s Disease Specialist Nurse and Community Link Nurse, however, services provided by specialist nurses must be carefully planned to account for increased service demands as services grow and develop. Activities and service time should be carefully logged and shared with managers to ensure services are not relied on through good will but form agreed business plans to adequately fund or redesign service provided.

Initially an increase in service hours has been provided by increasing the Parkinson’s Disease Nurse Specialist hours back to full time. This has enabled a new business plan to be put forward the Isle of Wight Primary Care Trust requesting an increase in service provision or further service resign to meet the service needs for people with Parkinson’s disease

**References**

