An Evaluation of the Generic Neurology Nursing Service

Executive Summary

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All references that are referred to in this executive summary, copies of the data collection tools and letter of approval from the research ethics committees are contained in the main report.
Section 1 - Background

1. Background

Specialist neurology services in the Mersey region are provided by the Walton Centre for Neurology and Neurosurgery through a hub and spoke model based at the Centre. Neurology clinics and ward consultations are provided at satellite district general hospitals by visiting Walton Centre consultants, with most district general hospitals receiving two or more visits a week. On other days there is no specialist neurology provision, although patients with urgent problems may be transferred to the Walton Centre. Non urgent cases have to wait for the next neurology visit.

1.1 National Service Framework. (NSF)

The National Service Framework for long term neurological conditions aims to improve the care of people with long term neurological conditions.

Approximately 10 million people across the UK have a long term neurological condition, accounting for 20% of acute hospital admissions. A long term neurological condition is the third most common reason for seeing a GP. It is estimated that 350,000 people in the U.K. need help with activities of daily living because of a long term neurological condition and 850,000 people care for someone with a long term neurological condition. (DH. 2005)

The National Service Framework for long term neurological conditions was published in March 2005; it is the Department of Health’s strategy for the care of those affected by long term neurological condition. It focused upon the way that health and social care services support people to live their lives in regard to independent living, care planned around needs and choices of the individual, easier, timely access to services and joint working between agencies.

The National Service Framework recognises a deficit in some previous services and makes a series of Quality Requirements (QR) to adjust services accordingly that includes:
• A more coordinated person centred service including better information and care planning and prompt advice, support and information (QR 1)

• The need for better information, advice and support to families and carers (QR 10)

• Improved care of neurological patients in other care settings such as non-neurological wards and care homes (Q11).

Furthermore, there is a need for the improved provision of care by staff with expertise in neurological nursing who are familiar with the available services in the locality.

1.2 Generic Neurology Nursing Service

Clinical specialist nurses have undertaken this type of role and have run nurse led services which have been shown to be effective (Appleton & Sweeney 1995, De Broe et al 2001 and Hurwitz et al 2005). Generally these have been disease specific i.e. Parkinson’s disease, Multiple Sclerosis, Motor Neurone Disease and epilepsy and in the main they have been either hospital or community based with limited working relationships between both sectors.
Section 2 – Methodology

2.1. Generic Neurology Nursing Service

The commissioned research was to undertake an evaluation of the Generic Neurology Nursing Service based in Wirral University Teaching Hospital NHS Foundation Trust. This service comprises of one full time nurse with a specialist neurology background. The aim of the service was to cover hospital and community settings across the hospital and local primary care trust. The service commenced April 2008 and was planned to expand across the Wirral.

2.2. Aim

To explore patients/carers and health care professionals’ views and experiences of the impact of the Generic Neurology Nursing Service.

2.3. Objectives

1. To identify the impact of the GNN on patients’ symptoms, quality of life and treatment journey
2. To identify the impact of the GNN service on carers
3. To identify the impact of the service on health care professionals and other services

2.4. Research Design

The design of the study was agreed in consultation with the commissioners. To meet the aims and objectives of the study, an evaluation study was adopted, utilising multi method research methodology encompassing both quantitative and qualitative approaches. Consultation data was collected in clinic and three validated data collection tools were employed during the study namely; Measure Your Medical Outcome Profile (MYMOP) (www.pms.ac.uk/mymop) and ‘EQ-5D’ (www.euroqol.org) and COPE questionnaires. This was followed up by the use of semi structured interviews with patients and carers and allied health care professionals.

2.5 Ethics & Access

Approval was granted for the evaluation through the local NHS research ethics committee (08/H1005/84)
Section 3 – Results & Discussion

3.1. Establishing the Service

There were some operational delays in the establishment of the service and the first clinics were not operational until May/June 2008, with the community clinics delayed until December 2008. This impacted upon the evaluation and is discussed as a limitation of the study. Furthermore, ongoing problems regarding administrative support, location of the accommodation for the clinics etc persisted and clearly affected the establishment of the service. Several key areas of impact of the service have been identified from the evaluation, including the type of service provision that is being offered, as well as the impact on patients/carers and health care professionals.

3.2. Service Provision

Routine information was collected on all 143 patients who attended 254 consultations in the clinics during the evaluation period (July 2008 - April 2009). The average number of patients attending each clinic was 5 (5.52 mean). However, ongoing problems with the allocation of the clinic slots and lack of administrative support resulted in several clinics being under used.

Although the service is open to all neurological conditions, it was interesting to note that the main neurological conditions seen by the generic service was epilepsy with 107 (43%) of the consultations and Parkinson's disease 94 (38%) of the consultations. Yet for both of these conditions, there is access to specialist nursing services within the Wirral geographical area.

3.3. Referrals to the Service

One of the issues that became apparent during the evaluation was the lack of awareness of the service by health care professionals and potential service users.
However, as the service was starting to become established, it was clear that the referral pattern was changing. Initially the referrals had been allocated as follow up consultations (by the consultant neurologist) with 80% (199) referrals being made. However, 32 consultations were made due to deterioration in the patient’s condition. This included severe seizures and adverse side effects of medication.

It is estimated that 54 consultations with the generic neurology nurse prevented a GP visit and 184 consultations (74%) avoided an appointment with a consultant neurologist. This suggests the potential benefit of the service, as this group of patients may have presented at a hospital emergency department, or walk-in centre/primary care team where they would not have had specialist neurological advice. This may have led to a delay in the provision of the appropriate treatment/intervention and possibly resulted in a hospital in-patient episode.

During the evaluation 46 patients, who were too unwell to attend an out-patient clinic, were seen at home/care home by the generic neurology nurse. This review of these patients would usually have been undertaken by a physician (either GP or consultant neurologist). Furthermore 18 patients, who were hospital in-patients at Arrowe Park Hospital, were seen by the service to provide specialist advice and help to promote a timely discharge. This suggests a potential financial benefit of the service, with a reduction in hospital in-patient bed occupancy and use of a specialist nurse rather than physician. This is in keeping with the finding by Hurwitz et al (2004) who suggested that specialist nursing services are run at no additional costs and therefore a reduction in hospital admissions would potentially equate to a reduction in costs.

3.4. Health Status/Issues of Concern

The health thermometer, when considered by neurological disease categorisation, indicates that the average score for the patients with MS reported their health score as being 53 (where 100 is the best possible health), Parkinson’s disease reported an average of 65 and patients with epilepsy 70. When this is considered with the ‘EQ-5D’ data it is possible to gain some insight as to the problems that were affecting the patients and their overall health scores. As expected, problems with mobility were
reported by patients with MS and Parkinson’s disease. Furthermore 57% (23) of epilepsy patients and 47% (15) Parkinson’s patients reported some problems with anxiety/depression. When this data is examined in more detail 18 (45%) of the patients with epilepsy recorded a 2 (some problems) and 5 (12%) of the patients recorded a 3 (severe problems). This potentially suggests that some of the patients may require further investigation of the level of anxiety and depression. However as the research team did not have access to the patients’ case notes, it is not possible to assess if this was a problem that was already being managed.

3.5. Reported Interventions made by the Generic Neurology Nurse

All interventions made during the consultation with the generic neurology nurse were recorded at the end of the consultation. The majority of the interventions focused upon medication advice and education.

3.6. Medication Advice and Education

Medication advice and education, as part of the specialist nurses role, has been reported in previous studies (Risdale et al, 1997). In this study 65% of consultations included some advice regarding the patients’ current medication. This included adjustment to dosages (49%), commencing new medication (20%) and discontinuing medication (4%). This also included the emergency management of epileptic seizures through patient and carer training on administering Midazalam. This drug is a recommended substitution for rectal diazepam (NICE 2004) this medication can potentially prevent emergency admission to hospital.

This aspect of medication advice was also reported in the patient interviews, with one respondent referring to the video they were provided with on this treatment. The provision of education to both patients 59% (147) and carers 27% (69) was also recorded. This was illustrated in the patient and carer interviews as being around medication management; additionally the promotion of the self management of the condition was also reported. This finding is supported by the literature where Shaw et al (2007) reported on a self management programme for patients with epilepsy.
3.7. Referrals to Other Health-Care Professionals and Services

16% (40) of patients were referred to another allied health professional service, including the continence team, optician services, physiotherapy, occupational therapists, psychological services and dieticians. Interestingly only 3% (7) of consultations resulted in patients being referred to social services, which is in keeping with the study by Kirker et al (1995) who reported referrals to other service including for respite care.

Referrals to other health care professionals and services were also reported in the patient interviews, with reference to referrals to services such as physiotherapy. One carer identified how there had been the offer of respite care, whereas another respondent referred to how they had been told to contact the Generic Neurology Nursing Service who could have arranged some temporary additional care, in the form of meals-on-wheels during a recent period of illness.

3.8. Patients’ Views of the Service

The interviews with the patients and carers, indicated a high degree of satisfaction with the service. In particular they referred to the time provided for the consultation and the benefits of a specialist nurse led service, factors which are clearly linked.

3.9. Consultation Time

The respondents in this study reported the benefits of a longer consultation time coupled with the opportunity to talk freely about their symptoms and to ask more questions. Respondents commented on the amount of detail that the generic neurology nurse went into and how they felt this to be advantageous. An increased understanding of their symptoms and the disease pathway were also reported. This increased time also enabled them to gain more knowledge about their condition and how to successfully manage it. This increased knowledge of their condition was also found in the studies by Kirker et al 1995; Forbes et al 2006, Shaw et al 2007. Furthermore, it is in keeping with the recommendations of the Department of Health
(2006) White Paper, which emphasises that self care and self management are to be embraced.

3.10. Nursing Led Service

Previous studies evaluating clinical nurse specialists have indicated a high degree of patient satisfaction (Wade and Moyer 1989, Hill et al 1994, Kirker et al 1995). They have shown that generally patients do not have any concerns in seeing a specialist nurse rather than a physician. The patients strongly reported that they felt the nursing led service to be comparable to the medically led service. Respondents reported that they felt confident in being seen by a specialist nurse rather than a physician. The advantage of being followed up by the same person resulting in a continuity of care was stressed by several respondents, and also impacted on appropriate referral to other service. One main advantage of attending a nurse led service was the additional support and access that was provided. This included a mobile telephone number to call for advice and support.

3.11. Carers

The data from the carers was obtained via the COPE Inventory and focused on how they were coping as a carer and the semi structured interviews that explored their views of the Generic Neurology Nursing Service

3.12. Carers’ Views on the Generic Neurology Nursing Service

The comments from the carers obtained from the joint carer/patient interviews were focused on their experience of the Generic Neurology Nursing Service and they commented that they felt supported by the service. This in particular focused on the opportunity to find answers to the many questions that were worrying them about caring for a patient with a long term neurological condition. This point of being able to obtain more information being a benefit, was a finding reported by Appleton and Sweeney (1995).
Positively the carers reported that the burden of care lessened somewhat by having a designated point of contact. In particular they liked the provision of a telephone number to call if they required help or advice between appointments.

3.13. Health Care Professionals
The health care professionals who were interviewed, included a sample of allied health professionals physicians, community based nursing staff and hospital ward based nurses, and all reported positively about the value of the service. Interestingly respondents who were physiotherapists highlighted the need for an earlier referral to physiotherapy services for patients with Parkinson’s disease, as they could have provided help to them earlier in the disease trajectory. Additionally one of the physicians made reference to the patients’ experience and how having a key contact in the generic neurology nurse could help that experience, particularly following diagnosis. Indicating that the time for the referral to the neurology nursing service is worthy of consideration.

An additional impact of the generic neurology nurses was that of the need for education by the general nursing staff. This finding is not unexpected and is in keeping with previous studies evaluating specialist nursing services both in chronic conditions and palliative care.

3.14. Summary
The patients’ self recording of their health scores indicate that poor health is being reported by many of the neurology patients, with the maximum score (best self reported health score) by the patients with epilepsy. The findings from this study indicate that the Generic Neurology Nursing Service is having a positive impact on patients, their families and health care professionals. In particular the service appears to be making interventions particularly around medication advice and education especially for patients with epilepsy.

Interventions are made that may have resulted in the patients symptoms being controlled faster, which undoubtedly impacts upon the patients’ and carers’ quality of life. Financial implications can also be suggested, particularly in reducing inappropriate attendances at, for example, accident and emergency departments.
and possibly reducing hospital in-patient bed occupancy. The avoidance of a consultation with a GP or consultant neurologist, by the use of the Generic Neurology Nursing Service, can be suggestive of financial savings, although further research including a full economic evaluation is undoubtedly required to confirm this.
Section 4 - Limitations of the Study

4.1 Service Development
Currently the service is still being developed and the set-up of the community clinics is only starting to emerge. This ongoing delay has impacted upon the evaluation and although data collection was extended by five months, at the time of reporting the service is still under development.

4.2 Carer and Patient Interviews
The original design of the study was to interview the carers separately, however as the access to the carers was via the patients, when the interviews were undertaken, generally the patients stayed in the room with the carers.

4.3 Administrative Issues
Throughout the evaluation the service has been fraught with administration problems, which have had a direct impact on the number of patients who were seen by the service. Additionally many of the initial contacts with the service were not actually direct referrals, but follow up consultations that would have been seen by the consultant neurologist. This potential element of bias has to be noted and further research, once the service is operational, is required.

The reported interventions were recorded by the generic neurology nurse after the clinic visit. Due to the lack of access by the research team to the medical records (ethics committee requirement) it was not possible to confirm the accuracy of this data. Clearly a retrospective case note audit would be of value to ensure validity of this data.

However, despite the reservations noted above, the findings are in keeping with the findings from previous studies.
Section 5 - Conclusion and Recommendations

5.1 Conclusion

This preliminary evaluation of the Generic Neurology Nursing Service has suggested that the role is appearing to have a positive outcome on patients and their carers. With approximately 10 million people across the UK having a long term neurological condition, coupled with an increasing aging population, the needs of this patient group and their carers cannot be underestimated (DH.2005).

Changes in service delivery to provide generic neurology nurses clearly have the potential to provide support for the patients and their carers. Therefore it goes some way to meeting the quality requirements (QR) of the National Service Framework for Long Term Conditions (2005) namely: the provision of ‘a more coordinated person centred service including better information and care planning and prompt advice, support and information’ (QR 1) ‘providing better information, advice and support to families and carers’ (QR 10) and ‘improving care of neurological patients in other care settings’ (Q11).

5.2 Recommendations

1. Currently the service appears to be focusing on patients with epilepsy and Parkinson’s disease, particularly on medication changes and education. This finding was unexpected, as the Wirral area already has an established epilepsy and Parkinson’s’ disease service in existence, including specialist nurse led clinics. A review of the current system for the management of patients with these conditions is suggested.

2. The administration and organisation of the clinics and particularly the appointment system appears to have ongoing problems. This is clearly having a negative impact on the establishment of the service and a review of the service is urgently required.
3. The referral system to the service is still in its embryonic stage, and a system for referrals is required that is rolled out across the catchment area. Consideration of the development of a referral pathway for the service is recommended.

4. The ward-based staff identified the need for education around the management of neurology patients. A programme of education or even the development of a link nurses system to enhance patient care is worthy of consideration.

5. The service comprises one specialist nurse and there is no system in place to provide adequate cover for leave/absence. It is suggested that this is reviewed and a system established to provide for this cover to ensure the ongoing provision of the service.

6. A full evaluation of the service is recommended, once operational at full capacity for one year, which includes an economic evaluation.