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# The Development of a Holistic, Community Based Neurorehabilitation Service in a Rural Area

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Brain injuries have devastating effects for individuals and their families. As in other countries brain injuries are common in the United Kingdom (UK). It is estimated that approximately 100 - 150 per 100,000 of the general population are disabled as a result of a traumatic brain injury (British Society of Rehabilitation Medicine, 1998). Brain injuries are, however, not limited to trauma. Cerebrovascular accidents are another leading cause of brain injury and it is reported that 1.6 – 2.0 per 1000 of the general population in the UK suffer a first stroke each year (Bamford, Sandercock, Dennis et al 1988).

With the dramatic advances made in medical care over the last couple of decades, individuals now often make a good physical recovery following brain injury. Significant developments in the acute care of brain injured individuals has resulted in substantial numbers of survivors living in the community with their families. This increased number of survivors often face a return to their communities without access to rehabilitation programs (Greenwood & McMillan, 1993). It appears that the cognitive, behavioral and emotional difficulties following brain injury pose the greatest obstacles to rehabilitation and also re-employment (Lishman, 1998; Ponsford, Olver & Curren, 1995). The physical, psychological and cognitive effects of a brain injury have been well-described (Lezak, 1995; Lishman, 1998).

North Wales is a rural area on the northwestern coast of the United Kingdom. Both Welsh and English are widely spoken in North Wales. It is an area of outstanding natural beauty. Important sources of economic activity include farming, light industry and Eco-tourism. North Wales has a population of approximately 660,000.

While data regarding the incidence and prevalence of traumatic brain injury for North Wales is limited, preliminary results of surveys appear to reflect national UK data (Coetzer, 1999; Elliston & Rogers, 1996). It has been anticipated that there may be approximately 1,000 survivors of brain trauma with long-term disabilities living in this community (Report of the All Wales Steering Group, 1997).

The North Wales Brain Injury Service (NWBIS) has a North Wales remit, spanning six local authorities. The Service is hosted

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by the Conwy & Denbighshire NHS Trust, one of the three National Health Service (NHS) Trusts in the area. It is located in Colwyn Bay, a coastal town of North Wales. No community based brain injury rehabilitation service existed in this area prior to the establishment of the NWBIS.

There are three District General Hospitals (DGH) in the area, but no specialist inpatient unit for patients with brain injuries. The DGH provide acute care for brain injured patients. Some sub-acute patients are referred out of area for inpatient rehabilitation. The regional Neurosurgery Unit serving North Wales is located in Northwest England (Liverpool). Visiting neurologists from Liverpool provide a service to patients in North Wales.

A Welsh Office investigation into service provision for brain injured individuals during 1995 identified significant gaps in service provision for individuals with a brain injury and their families (All Wales Steering Group, 1997). Prior to 1995, the voluntary organisation Headway played a major role in lobbying for a brain injury service. During 1997 the North Wales Acquired Brain Injury Strategy Group (NWABISG) was formed to steer the development of services in the region. The NWABISG had representation from the voluntary sector (Headway), medical professionals, commissioners of services (North Wales Health Authority), the local clinical psychology department, social services, public health physicians, therapy services and other stakeholders.

The first appointments to the NWBIS were made during April 1998. The initial remit of the NWBIS was to provide an assessment and consultation service for adults with an acquired brain injury. However, the remit broadened very rapidly to include direct rehabilitation interventions. Several additional appointments to the service were made during 1999–2002. During March 2001 the staff of the NWBIS moved into a community based brain injury rehabilitation unit on the Colwyn Bay Community Hospital site.

The NWBIS is multidisciplinary with input from clinical neuropsychology, neurology, occupational therapy, social work, physiotherapy, speech and language therapy and rehabilitation assistants. The clinical remit is to see individuals of any age with moderate to severe acquired (non-progressive) brain injuries. The Service accepts referrals of non-progressive neurological conditions including traumatic brain injuries, cerebro-vascular accidents, tumours and CNS infections. Traumatic brain injuries make up the bulk of the referrals (Coetzer, 1999). The Service has no upper age limit for most types of referrals and has seen several

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older adults with an acquired brain injury (Coetzer & Abson, 2001).

The Service works with other health and social services and voluntary sector organisations in the community wherever possible. Close links exist with the University of Wales Bangor School of Psychology as well as the School of Nursing. The NWBIS offers specialist placements for clinical psychology and other students. Opportunities for collaborative research and teaching activities exist between the University and the Service.

### **Theoretical Model**

The effectiveness of brain injury rehabilitation is strongly supported (Cope, 1995). However, no single profession in isolation can serve the complex needs of individuals with a brain injury (Rose & Johnson, 1996). Indeed, Semlyen et al (1998) came to the conclusion that superior outcomes were associated with a specialist multi-disciplinary regional service.

Alexander R. Luria's theoretical principles underpinning neuropsychological rehabilitation models are the most influential in approaches to brain injury rehabilitation (Uzzell, 1997). Wilson (1997) provides a review of the four main approaches to brain injury rehabilitation. These include the cognitive re-training approach, the cognitive neuropsychological approach, the combined approach and the holistic approach (Wilson, 1997). Ben-Yishay (2000) and Prigatano et al (1994) give more detailed descriptions of holistic, neuropsychologically orientated milieu programs. In this type of program, the patient's individual needs determine the individual therapies they receive. In addition, patients receive group and individual psychotherapy. The therapeutic interventions of the program are embedded in the milieu program, emphasizing social interaction and integration. Essentially these programs are concerned with increasing awareness and acceptance, providing compensatory strategies for cognitive problems and vocational interventions (Wilson, 2002). Clinically there seems to be few concerns with the holistic approach and patients appear to benefit from improved productivity and self-esteem (Wilson, 1997). The approach does, however, require high levels of staffing.

Barnes (1995) asserts that a regional brain injury rehabilitation service should be located within a local community. Cognitive rehabilitation should focus on real life problems (Wilson, 2002). An important advantage of a community-based service is the potential for real life experiences and the implications this has for generalization of therapeutic gains. It is also more likely to

successfully include family members in the rehabilitation process.

The NWBIS provides what can essentially be described as a holistic program delivered on an outpatient basis, within a rural community. Interventions are individualised based on an assessment of needs in each case. Bajo and Fleminger (2002) in their recent review emphasize the importance of a patient centered approach when designing rehabilitation interventions for the individual. In the NWBIS patients may access individual as well as group based interventions and attempts at re-employment or education locally are made as part of a multi-disciplinary intervention. Interventions are provided at the unit, a DGH, community hospitals, GP surgeries or the patient's home, among others.

### **Programme Description**

#### **Referral Criteria**

The remit of the NWBIS is to assess individuals with acquired brain injury and to develop comprehensive management plans. Appropriate patients for referral are those with an established diagnosis of an acquired brain injury who have, or are expected to develop, chronic disability needing a long-term, multi-disciplinary, community-based rehabilitation program.

- I. Inclusion Criteria: Most of the patients meeting these criteria will have one of the following neurological disorders:
  - Traumatic brain injury.
  - Hypoxic brain injury.
  - Brain infection due to meningitis or encephalitis.
  - Stroke due to aneurysmal subarachnoid haemorrhage.
  - Intracerebral haemorrhage.
  - Young people with ischemic stroke (Rehabilitation services for older stroke victims are provided by care of the elderly consultant-led teams. These, however, do not have neuropsychological support and the NWBIS may be consulted for neuropsychological assessment of these patients in selected cases).
- II. Exclusion Criteria: The Service is not currently configured to provide care for patients with:
  - Recent mild head injury and post-concussion syndrome of less than 6 months duration.
  - Progressive degenerative or other dementing illness.
  - Congenital or developmental neurological or psychiatric disorders.
  - Brain disorders attributable to toxic effects of alcohol or

drugs.

- Neuropsychiatric complications of primary epilepsy.
- The Service does not function as a “memory clinic” for the diagnosis of patients with memory or other cognitive complaints of unknown aetiology.

### III. Referral Screening

Referrals are accepted from medical practitioners and screened on a weekly basis by clinicians under the guidance of a consultant neurologist. When information in the referring letter does not document the presence of a chronic acquired brain injury, or detail the severity of the injury necessitating long-term, multi-disciplinary rehabilitation, the referring doctor is contacted and asked to provide further information and the neurologist obtains relevant medical records and scans. These are reviewed to document:

#### A) Aetiology:

- Is there an established diagnosis of an acquired brain injury due to one of the disorders listed in I above.
- Is there an established diagnosis of one of the disorders listed as exclusion criteria in II above.

#### B) Severity:

To determine whether the need for chronic, multi-disciplinary rehabilitation has been established, records are examined to define the current degree of disability and to document whether the precipitating injury is classified as moderate - severe. For cases of traumatic brain injury, the records are reviewed to determine the chronicity of the disability as well as the severity of the precipitating injury based on the following criteria:

- History of the injury
- Glasgow coma scale (<13)
- Duration of retrograde and post-traumatic amnesia
- CT or MRI evidence of intracranial pathology

## Assessment

Acceptance of a referral is followed by an initial generic clinical assessment. The initial assessment covers in depth the presenting complaints, details of the injury, developmental and medical history, clinical bedside cognitive screening and a collateral interview with a carer. Where possible, initial outcome data are collected.

Often more profession specific assessments, for example psychometric, neurological, social work or occupational therapy assessments follow. At a weekly referral and case review meeting the treatment plan for an individual patient is formulated and the assessment or intervention of other clinicians within the Service requested. This is a dynamic process and recently care pathways were developed for the Service. These pathways describe the flow of patient care from the acute to the post-acute community phase.

## Rehabilitation Interventions

Patients can access any combination of the following individual interventions, based on their needs as identified during the initial assessment:

- Psychotherapy, for both patients and carers, often

focussing on coming to terms with the brain injury

- Speech and language therapy, sometimes including communication aids
- Occupational therapy, including vocational rehabilitation as well as functional adaptations
- Physiotherapy, including rehabilitation for balance problems and motor disabilities
- Neurology follow up and review, provision of medical information
- Social work, including advocacy, assistance with benefits and discharge liaison
- Anxiety and anger management interventions
- Clinical neuropsychology, including compensatory strategies for cognitive difficulties

The following group based interventions are provided for patients and carers:

- A memory & concentration group focussing on compensatory strategies
- A monthly drop-in carer support group
- An occupational therapy group for daily living skills
- A discussion & current affairs group

Patients are reviewed regularly by clinicians involved in their care. A specific strength of the program is the provision of neurology reviews. Discussion of assessment results, review findings and therapeutic plans with patients and carers are core aspects of the program. This potentially assists with increasing the self-awareness of patients. Carers are closely involved in interventions and often attend consultations. In addition feedback is obtained from carers on some of the outcome measures.

## Outcome Measures

Outcome measures have an essential role in the process of developing and refining rehabilitation programs. The NWBIS collects the following outcome data: Standardized questionnaires, employment information, and placement data. These are described in more detail below.

The European Brain Injury Questionnaire (EBIQ) (Teasdale, Christensen, Wilmes et al, 1997) is a questionnaire consisting of 63 items related to common difficulties experienced by individuals following brain injury. Items are rated on a three-point scale (0 = ‘not at all’, 1 = ‘a little’ and 3 = ‘a lot’), regarding the preceding month. The patient and a carer or family member complete the two parallel forms independently. The questionnaire has acceptable reliability and validity (Teasdale, Christensen, Wilmes et al, 1997).

Employment outcome is rated as follows: 1 = change from employed to unemployed; 2 = change from employed to part-time employment; 3 = no change (including unemployed to unemployed as well as employed to employed at same level); 4 = change from part-time employment to full-time employment and 5 = change from unemployed to full-time employment.

Residential outcome is determined by using the final placement rating score on Eames’ (1999) Grafton Manor Study Hierarchy of Placements (GMSHP). The GMSHP is a scale used for rating change in placement status following brain injury. Only

the final placement rating is used by the Service, in view of the rural nature of the area where the service users live (with no inpatient brain injury rehabilitation services available and hence little opportunity to obtain a realistic change score).

It is envisaged that in the future more use would also be made by the service of other outcome measures, for example the Brain Injury Community Rehabilitation Outcome (BICRO) scale (Powell, Beckers & Greenwood, 1998).

### **Outcomes: Preliminary Results**

A recent review of all clinical records in the Service revealed an initial cohort of 24 patients for who baseline and repeated outcome data of the European Brain Injury Questionnaire (EBIQ) were available. Of the 24 patients included in this review, 16 (66.7%) were male and 8 (33.3%) were female. The average age of the participants was 39.3 years (SD = 12.8, range = 20 - 63). The severity of brain injury was classified as follows for the present sample: mild = 2 (8.3%), moderate = 3 (12.5%) and severe = 19 (79.2%). Individuals were rated as having sustained a severe injury (GCS 8 or lower or LOC more than 24 hours); moderate injury (GCS 9 – 12 or LOC between 30 minutes and 24 hours) or a mild injury (GCS 13 – 15 or LOC less than 30 minutes) (Guilmette, 1997). The two individuals' classified initially as having sustained mild injuries had problems extending well beyond six months post injury. The average time since injury was 67.9 months (SD = 85.4, range = 3 - 324). Of the 24 patients, 21 (87.5%) sustained a traumatic brain injury and 3 (12.5%) sustained a cerebro-vascular accident. All patients received individualized, multidisciplinary community based rehabilitation.

The average time between administering the first and second EBIQ respectively was 10.1 months (SD = 3.8). A Wilcoxon comparison revealed a significant improvement in the subjective self-report of symptoms among participants ( $T = 53$ ;  $p = .0056$ ), whose mean total EBIQ scores were reduced from 127.9 to 114.5. However, while carers' EBIQ ratings decreased from a mean score of 124.3 to 119.4, this did not reach statistical significance ( $T = 83$ ;  $p = .4115$ ).

The average time since injury was 67.9 months. In most cases it was unlikely that the improvements reflected on EBIQ scores were attributable to spontaneous recovery, which often continues to be observed over the first two years following injury. However, as seven patients completed their first EBIQ within two years post injury, we also compared patients' ratings with this sub-group of recently injured patients excluded. The repeated EBIQ ratings for this group ( $N = 17$ ) also showed a significant decrease in mean EBIQ scores ( $T = 26$ ;  $p = .0168$ ).

### **Discussion**

Post acute brain injury rehabilitation poses significant challenges to clinicians and probably more so in a rural area with limited access to resources. This paper described the development and functioning of a community based holistic rehabilitation program for brain injured adults. Preliminary outcomes were also reported. Long term observational studies have an important place in the evaluation of benefits of treatment in lifelong conditions (Elphic, Tan, Ashby & Smyth, 2002).

The preliminary results reported in this paper were

encouraging, with 71% of service users having rated themselves as improved. Carers, however, did not rate the significance of improvements to the same degree. It was thought that this might be a reflection of a need to provide more information and support to carers. As a result, a monthly drop-in carer support group was started.

Achieving measurable real world outcomes remains a challenge. Re-employment appears to be difficult to achieve in this rural area, for various reasons, including a shortage of potential employers (Coetzer, Hayes & du Toit, 2002). In addition, some outcome measures currently in use by the Service are perhaps too clinician centered. Goal setting with patients and carers may serve to make the process of outcome measurement more patient-centered.

Future research assessing the effectiveness of community rehabilitation programs should focus on ecologically valid outcomes, for example placement and change in employment status. These data are collected by this Service and will be used in future studies to report on the effectiveness of the program.

A strength of the NWBIS rehabilitation program is the individualized nature of interventions. However a stronger focus on group intervention is being considered to strengthen the program. An information and support group is being planned. It is envisaged that this group intervention will foster patient engagement in the therapeutic process and improve patient allocation to specialized groups. These specialized groups may potentially include additional cognitive remediation groups, group psychotherapy, and groups for vocational skills and activities for daily living.

This program description did not specifically address the needs of children with a brain injury. Brain injury services for children have traditionally not been as well developed as those for adults (Appleton & Baldwin, 1998). Neurological and life stage developmental issues have a significant influence on children and consequently on rehabilitation needs and services.

The NWBIS has recently initiated a pediatric service to address the rehabilitation needs of children. The current focus is on the development of professional links across North Wales and on the development of a clinical service. This clinical service is currently aimed at providing multi-disciplinary assessment and consultation to other community professionals, family information and support, and direct psychological and occupational therapy interventions.

Integrating biological, psychological, vocational and social elements of rehabilitation within a community based holistic neurorehabilitation program can potentially achieve positive outcomes for brain injured individuals. The individualized nature of the multi-disciplinary interventions for patients of the NWBIS is one of the most important strengths of the program. Providing these interventions within the community where individuals live, enhances the opportunity for generalization of therapeutic gains.

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