

Report for Travelling Scholarship to BSRM 2008

During January 2008 I visited two rehabilitation centres over 8 days in the eastern United States. This visit arose out of a personal interest to gain some insight into the nature of rehabilitation services available abroad and was supported in part by a travelling scholarship kindly provided by the British Society for Rehabilitation Medicine. The US was an obvious choice for me because I have relatives there, there is no language barrier, and I am aware that some rehabilitation services are particularly well established.

The objectives of my visit were to:

- understand organisational aspects of rehabilitation services in the US
- learn about different approaches to neurological rehabilitation including an understanding of how best practice is identified and delivered
- understand the impact of funding on health and rehabilitation services in the US.

Background

My interest in these issues evolved during training as I began to appreciate that patient management and treatment is strongly related to the way services are organised locally and to the team members who deliver them. I am most familiar with the Neurorehabilitation unit in Reading and the Oxford Centre for Enablement where I worked during my training but I saw different ways of organising services when visiting other NHS rehabilitation units in Derby, Cambridge, Southampton as well as the Headley Court Defence Medical Rehabilitation Centre. I have also visited several private units within the UK: the Oliver Zangwill Centre, Cambridge; Ravenswood Village, Berkshire; Queen Elizabeth's Foundation Brain Injury Centre, Surrey and the Kemsley Unit at St Andrews group of hospitals in Northampton. Having seen these units within the UK, I wanted to be able to compare what I saw with some services abroad.

Overview

Rehabilitation units in the UK tend to be organised around neurological disease, spinal injury or musculoskeletal disease including prosthetics, with most units concentrating on neurological disability. Conversely, in the US, I found that the two rehabilitation centres I visited were larger with all types of rehabilitation offered

within the same unit. However, it was clear after speaking to several doctors that both centres were considered fairly unusual even for the US and that in many parts of this vast continent there may not be as comprehensive rehabilitation facilities for miles around. Both centres are also considered amongst the best in the US.

The Kessler Institute for Rehabilitation (KIR) based in northern New Jersey was founded in 1948 and now has over 240 licensed rehabilitation beds on three sites. It provides in- and out-patient rehabilitation including spinal cord injury and traumatic brain injury programmes, case management, stroke, amputee and orthopaedic programmes and pain management. The KIR also has a sister research and education organisation, the Kessler Medical Rehabilitation Research and Education Corporation (KMRREC) which has 72 employees including 12 PhD / MD full-time researchers.

The MossRehab Centre based in Philadelphia, Pennsylvania is an organisation with around 120 rehabilitation beds and 60 acute beds on several sites, which began over 100 years ago as a tuberculosis hospital and developed in the 1950's to provide a range of rehabilitation programmes.

Both organisations are recognised as centres of excellence for treatment and research related to brain injury, and are also accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). This is a non profit organisation that has developed standards of rehabilitation and accredits providers who meet them.

The US has 9000 registered physiatrists (rehabilitation physicians) and 300 doctors graduate in rehabilitation board exams annually. This compares with 250 rehabilitation consultants in the UK with about 15 graduating with a Certificate in Completed Specialist Training (CCST) annually.

Organisation of services

In-patient services in both centres are arranged according to diagnosis, with wards devoted to brain injury, stroke, general rehabilitation including amputation / post-arthroplasty rehabilitation, and spinal cord injury. Most patients are transferred to the rehabilitation centres as soon as they are medically stable (no longer requiring close monitoring) so they can be on-site within a few days of the acute event, especially in relation to stroke patients. This service is rather different to most rehabilitation

centres which I have seen in my training, where patients arrive in the rehabilitation unit anytime from a week or two to a couple of months post-event.

This is made possible because, for instance at the MossRehab, a large proportion of beds are also for acute neurology and medical patients and this, along with a post-op ICU facility provides back-up for patients who suddenly deteriorate and allows the hospital to more safely accept acute rehabilitation patients. Theatres are also run on-site to provide a service for elective joint replacement and baclofen pump insertion.

Complications associated with traumatic brain injury, such as autonomic dysreflexia and behavioural problems associated with post-traumatic amnesia, are regularly managed in the rehabilitation ward. However, I also became aware of some patients with traumatic brain injury who were not seen for many weeks or months after the acute event and resided in 'skilled nursing facilities' in the meantime. This situation was sometimes related to insurance issues. Patients are funded for a limited time period and staff attempt to work with patients to offer the treatment period at the point after injury when it is thought that rehabilitation would make most difference. In many cases this is as soon as possible, but in some cases rehabilitation is deliberately postponed. The usual problem of having a waiting list for admission in the UK did not seem to be an issue in the centres visited.

At the Kessler, therapy sessions are organised so that three hours total of combined occupational therapy and physiotherapy is provided for each patient, divided into two sessions of an hour and a half each in the morning and afternoon. Therapy is offered at weekends if a patient has missed sessions during the week. Speech therapy and psychology sessions are in addition as required. The environment of the ward and therapy areas was very spacious compared to many centres in the UK. I think this reflects the increased availability of land in the US so that the standard size of many homes and buildings is much larger than in the UK.

At MossRehab a short multidisciplinary team (MDT) meeting is held daily and a provisional discharge date is discussed on admission. Goals are set in therapy sessions and each patient's goals are reviewed weekly at one of the MDT meetings. Both centres routinely document disability and impairment measures.

Approach to rehabilitation and implementation of best practice

There is a greater emphasis on discharge or 'next level of care' which is inevitable when resources are externally limited. This may mean that rehabilitation programmes appear to be more efficient than in the UK in terms of discharging patients. However, although the US in-patient rehabilitation programmes improve basic functional activities they do not appear to address longer term participation issues. The MossRehab brain injury programme policy document states that inpatient management emphasises 'required skills for activity pattern functioning such as feeding, drinking, bathing, communication...as well as basic skills of cognition and social behaviour which allow for safe management outside the hospital setting'. I met the wife of a patient in a low awareness state who cared for him at home with 4 hrs of care per day except at weekends when 2 hours per day was available. Such a patient in the UK would probably be in a residential home.

There are several outpatient programmes described which address community roles and work issues but I did not have a chance to see any. I suspect that, because of financial limitations, not all patients will have access to the rehabilitation required to reach all participation or vocational goals. In a throwaway comment, one physician said that 50 million or more Americans are one illness away from being destitute.

US physiatry trainees who I spoke to were not aware of the WHO International Classification of Functioning. The rehabilitation in-patient services appear to be configured much more tightly around the medical model. Diagnostic EMG is the domain of rehabilitation physicians as well as neurologists, and drug intervention is more widely used to try and facilitate therapy in comparison to the UK.

Both centres are actively involved in many research programmes. These include a randomised controlled trial on amantidine in the vegetative state, a study of intensity of rehabilitation, length of stay and outcome in MossRehab; and at Kessler, aphasia studies and the development of a research tool to assess outcomes for traumatic spinal cord injury. I was expecting to see much more use of outcome measurements, in particular goal attainment scaling, but this was not the case. The MossRehab Brain Injury Centre uses a FIM flow sheet for each patient and when appropriate, the Disability Rating Scale, Coma Rating Scale and the MARS - Moss Agitated Behaviour Scale.

Both centres are also part of the TBI Model Systems which is a joint research programme sponsored by a government body. Centres contribute data to a national longitudinal database used to provide data on TBI outcomes. Patients admitted to an accredited unit are included in the collected data. In Philadelphia, patients could be placed in one of three local brain injury units and the one chosen may depend on the insurance company and family opinion based on reputation and possibly location. Only the MossRehab centre is part of the TBI Model Systems so if patients go elsewhere in Philadelphia their data is not included.

Funding issues

It is well known that healthcare in the US is financed through public (Medicare/Medicaid) and private (employer/individual) insurance along with personal financial contributions. In order to understand how rehabilitation services are organised and delivered in the US, it is necessary to appreciate the extent to which funding and reimbursement issues are integral to the development and definition of services. Providers of rehabilitation care must meet the legislative requirements set out by the government which define what constitutes a rehabilitation facility. This depends on intensity of therapy and case mix, whereby a proportion of patients must have one of a designated list of diagnoses (including stroke, traumatic brain injury, limb amputation). It is known as the 75% rule although the proportion of patients who must have one of the diagnoses has recently been reduced to around 60%. A notable exception from this list is arthroplasty.

Often the length of rehabilitation stay is limited by the number of days paid for by insurance. This is set by diagnosis rather than clinical condition and is rarely extendable; for stroke it is about 28 days. Occasionally, discharge may be delayed if the treating team feels it is unsafe and if extending rehabilitation would change this. In this case, the hospital keeps a patient on 'good will' on the expectation that the patient can claim back payment at a later date. One observation, no doubt related to this, is that Occupational Therapy home visits have been phased out, and home report papers are now sent out with relatives to draw out a floor plan and measure doorways, etc.

Despite financial constraints, there is evidence of innovation at both units. At the Kessler, therapy dogs were recently introduced and play a part in therapy sessions. The Kessler therapy gym contains a treadmill trainer with partial body weight support. At MossRehab, a cost-neutral day centre was set up to promote 'personal success and self-sufficient living' as it became clearer that some patients were being discharged with little social support. Several other developments are mentioned within the organisations' literature including the Kessler's 'Special Initiative' grants.

Conclusions

My very first impressions after a few days of seeing the rehabilitation centres were that NHS rehabilitation services actually provide more comprehensive participation focussed assessment and treatment. This was contrary to what I was expecting. However, I am aware that I did not see all services available in the two centres, particularly with regard to outpatient therapy, and it is likely that these services look at the participation side in more detail. I also did not have a great chance to talk to patients about their experience. Patients who I observed in medical outpatient appointments had varied funding arrangements (e.g. Workers Compensation, Head Injury Fund Philadelphia [HIP]) and this affected what they were entitled to.

Having reflected on my experience whilst writing this report, I believe that rehabilitation services in the UK do have something to learn from what I have seen in the US with regards to a more efficient in-patient programme. The problem for services in the UK is chronic under funding and understaffing which constantly thwarts efficient treatment, not only in rehabilitation. It was noticeable that the US centres did not appear to have the problems with staffing ratios which are present within the NHS.

By comparison with the UK, funding issues were more intrusive within the rehabilitation process in the US, from deciding length of treatment to equipment and outpatient support available on discharge. From the doctors' perspective, 'proving' that their input was necessary meant seeing and examining patients daily without fail, sometimes coming in on weekends. Most attending physicians were responsible for around 18 in-patients. The documentation of this assessment was very much about physical examination. This can be partly explained by the fact that many patients have more acute medical problems, but I think the main reason is the demand of a

payment-driven medical model of health care, which assumes that the doctor's intervention is about pathology-based assessment and examination.

Within the field of rehabilitation, this focus on pathology goes against the principle of assessment and management which takes place at other levels of disease impact, i.e. impairment, ability / activity and importantly, participation or maintaining roles. In my opinion this constantly reinforces the doctors' role in the US as medical diagnostician and reduces the opportunity to think about the clinical scenario in a broader sense. The clinical lead for participation/role level interventions becomes less clear and the chance of these issues not being addressed becomes greater.

Rehabilitation based on the model of activity and participation (in simple terms a non-diagnosis based model) can be used to provide for more realistic needs of people with long-term disability and complex needs due to neurological and other illnesses. The advantage within the NHS and social care structure in the UK is the opportunity to provide nationwide, integrated services at both an in- and out-patient level. At the same time, however, the US will always benefit from a much larger population, particularly concentrated on the East and West Coasts, which can support sizeable, highly specialised rehabilitation organisations.

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