‘Awaiting rehab bed’: the implications of delayed admission to rehabilitation after neurological injury

This summer I spent four weeks of my medical elective working with the neuro-rehabilitation team attached to a major trauma centre in south London. I divided my time between the acute setting and one of its associated specialist neuro-rehabilitation units, with the intention of following some patients through this early part of their rehabilitation.

Only two patients made the transition from the acute hospital into inpatient neuro-rehabilitation during my period of observation, one of whom I followed during the beginning of her stay in the rehabilitation unit. The two main issues I identified during my involvement in this patient’s case (which is presented briefly below) were (i.) the delay in her admission to the rehabilitation unit, and (ii.) the continuity of her care during this delay. These issues will be explored in terms of their possible effects on patients with neurological injuries, with reference to the relevant literature as well as to patient L’s own experience.

Patient L

The patient I met in the acute setting had been admitted in mid-July 2015 with a spontaneous right basal ganglia haemorrhage, complicated by intraventricular extension and raised intracranial pressure. This was treated neurosurgically with an external ventricular drain. She was accepted onto the waiting list of a specialist inpatient neuro-rehabilitation unit a little over three weeks after her initial admission, and remained on the waiting list for a further five weeks before a bed became available for her. In the interim, she was transferred between different wards three times, with associated changes in her therapeutic team (for example, during her time on a trauma ward she was treated by the peripatetic neuro-rehabilitation therapy team, whereas during her time on neurosurgical wards she was treated by the ward-based therapists). The question of whether her care should have been managed under the integrated stroke pathway was formally raised on two occasions, yet she remained under the care of the neurosurgical team until her discharge to the rehabilitation unit. She was

medically stable during her five-week waiting period and the main action point on her medical care plan was to await the availability of a rehabilitation bed.

Delayed access to rehabilitation?

Delays in the appropriate care and management of patients with acquired brain injury are strongly contraindicated in the hyper-acute phase, where the concept of 'time is brain' (as coined by Gomez[7]) has become well embedded in the relevant clinical guidelines (e.g. those for stroke[5,9] and head injury[11]). The imperative for timely diagnosis and management of patients with brain injury is driven by the goal of minimising secondary insult and thereby, over the longer-term, reducing disability. But there has perhaps been less emphasis on the possible impact of delays later in the process on patients' rehabilitation potential (and by extension, their long-term morbidity and disability).

The unfortunate (if inevitable) existence of such delays is widely apparent anecdotally, and obvious from even the briefest encounter with rehabilitation unit waiting lists. Published data on actual waiting times for transfer to rehabilitation in the UK could not be found, though this information is routinely collated in the UK Rehabilitation Outcomes Collaborative (UKROC) dataset. UKROC data supplied by my neuro-rehabilitation unit for the 2014/2015 period show that the average wait between assessment (of the patient's suitability for this unit) and eventual admission to the unit was 31 days. The current standards[3] for transition into rehabilitation services suggest that this should happen within two weeks of assessment, for transfer into a Level 2 rehabilitation unit (local specialist rehabilitation services, such as the unit I attended), and within six weeks for Level 1 care (tertiary specialised rehabilitation services). However, the standards document itself notes that '*the majority of rehabilitation services are not adequately staffed and resourced to meet the proposed response times, and…the standards given are aspirational'.*

This problem is not limited to the UK, nor is it attributable solely to limitations in the capacity of rehabilitation services as alluded to above. A study by Poulos and colleagues in Australia[14] that used utilization review technology to assess

appropriateness of patient bed days in acute care found that, for a group of stroke patients, only 49% of days spent in acute care actually met the criteria for this level of care. The commonest cause of the inappropriate occupation of acute care beds was delay due to awaiting an inpatient investigation or procedure, followed by delay due to awaiting review by a healthcare professional, though a significant proportion of patients were, like patient L, awaiting transfer to a rehabilitation bed (6.6%) or other discharge location (10.4%).

The impact of rehabilitation delay

What are the possible consequences of this delay for patients' rehabilitation? The idea that timely initiation of rehabilitation affects longer-term outcomes has been validated in animal studies of post-stroke recovery (e.g. by Biernaskie and colleagues[2]), as well as in cohort studies of stroke patients that suggest a critical time window of 'spontaneous neurological recovery' in the early days to weeks after stroke (see for example the work of Langhorne and colleagues, 2011[8]). Clearly, randomised controlled trials in this field are unachievable for ethical reasons, therefore the literature mostly relies upon retrospective comparisons to investigate this putative association. For example, a study by Salter and colleagues in 2006[15] conducted retrospective medical record reviews to examine the effects of early (i.e. within 30 days) versus delayed admission to rehabilitation after stroke, using FIM™[20] scores (Functional Independence Measure) to compare progress between groups. The FIM™ is a well-validated measure of the degree of assistance required by a patient across a range of domains that are important for activities of daily living, and is commonly used to assess patients' progress in rehabilitation. This study found that patients in the early admission group had higher FIM™ scores at admission and discharge, as well as shorter lengths of stay in the rehabilitation unit. Both groups made functional gains (as represented by change in FIM™ score) during their rehabilitation, but when the analysis was adjusted to take account of their higher FIM™ scores at the time of admission, it was apparent that the early admission group demonstrated greater gains. Both groups were similar in terms of age, gender, and side of lesion, though those in the delayed admission group were significantly more likely to have experienced haemorrhagic stroke than ischaemic stroke (and it is not clear that the authors conducted any further analyses to check

whether this group difference was independently associated with the FIM™ outcome measures). It should also be noted that no information was available to the researchers about the initial stroke severity or acute medical complications experienced by the patients (both of which could interact with the purported association between rehabilitation admission delay and rehabilitation outcome). Nevertheless, these findings have been supported in similar retrospective cohort studies such as those by Wang and colleagues[17,18] and these studies appear to have been more careful to acknowledge and control for the myriad factors that contribute to delayed rehabilitation admission over and above logistical and capacity issues (such as characteristics of the stroke, the patient's age, and the patient's co-morbidities).

This association has also been reported for other neurological patient groups, such as those with traumatic brain injury (TBI), though this body of work is not yet as substantial as that for stroke. A retrospective study of paediatric cases of moderate and severe TBI (as defined by initial Glasgow Coma Scale score)[16] found an association between delay in commencing rehabilitation and rehabilitation outcomes (measured using FIM™), which was significant for children with moderate TBI, though did not quite reach significance for severe TBI (reflecting the greater potential for rehabilitation and recovery in those whose initial injuries are less destructive). For adult patients with severe TBI, a Norwegian study[1] demonstrated better functional outcomes at twelve months (as measured by the Glasgow Outcome Scale Extended) for patients who were allocated to early intensive rehabilitation, compared to patients who followed a standard pathway to sub-acute inpatient rehabilitation. The latter study highlights an interesting question over what specific characteristics of early access to rehabilitation might be most important for generating a better rehabilitation outcome. In the study, early intensive rehabilitation was initiated in a dedicated suite of beds in the Intensive Care Unit (ICU), the 'Early Rehabilitation Section of the ICU' (ERSICU), as opposed to the traditional model of transferring neurological patients to a separate, specialised inpatient unit to commence rehabilitation (which is the model employed in most of the research into the inverse association between delay to rehabilitation admission and rehabilitation outcomes).

This implies that it may not be the admission to a specialist unit that is most

critical for optimising functional recovery, but the early application of a multidisciplinary rehabilitation model at a sufficient level of intensity, regardless of the actual environment in which this occurs (be it ICU, acute medical or surgical wards, or district general hospitals). Indeed, this is suggested as a reason why some studies have failed to identify an association between delay to rehabilitation admission and rehabilitation outcomes, such as the study by Gagnon and colleagues[6]. In this retrospective review of stroke patients discharged from a Canadian specialized inpatient rehabilitation program, the researchers did not find any significant difference in outcomes (as measured by FIM™) between groups of patients with a short (less than 20 days), moderate (20-40 days) or long (more than 40 days) interval between their stroke onset and their rehabilitation admission. Groups were matched for age, gender and stroke severity (the latter characteristic is notably not controlled for in some of the studies that did find an association between delay and rehabilitation outcomes, such as that of Salter and colleagues[15]). The authors hypothesise that any negative effects of delayed admission to a rehabilitation unit were forestalled by the services offered within the acute care setting, where inpatient rehabilitation (here defined as physiotherapy, occupational therapy, and speech and language therapy) was rapidly initiated after initial stroke onset (usually within 72 hours). This is similar to the provisions for acute care in the UK, where early rehabilitation is embedded in practice and supported by the relevant clinical guidelines (such as those for stroke[5] and for rehabilitation after critical illness[10]). As yet there does not appear to have been any evaluation of the cost effectiveness of establishing rehabilitation in acute and critical care settings, nor of the ideal model for delivering this service, though a recent position paper[19] from the European Union of Medical Specialists (Section of Physical & Rehabilitation Medicine) supports a model in which dedicated rehabilitation beds, under the supervision of a specialist in rehabilitation medicine, are provided within the acute care setting.

Continuity of care

One of the advantages of such a model, which is particularly pertinent to the case of Patient L, is that it would establish a continuity of care for the patient within a dedicated rehabilitation pathway, even while they remain in the acute hospital setting.

Patient L was not cared for under the remit of an integrated stroke pathway, for reasons not explicitly provided in her patient record but possibly related to the fact that the initial management of her injury was neurosurgical. Consequently, she spent the remainder of her inpatient admission being transferred between different neurosurgical and trauma wards (instead of in a dedicated stroke unit), with corresponding changes in the staff responsible for her early rehabilitation (from various disciplines including physiotherapy, occupational therapy, speech & language therapy and social work). In my visits to her during this period, she was often confused (with GCS of 14/15) and made frequent references to staff members who were not known on her current ward, as well as complaints about people who '*said they would come back and never did.*' It is possible that her distress would have been lessened had she been cared for in a more consistent environment that took account of her cognitive and emotional needs. These are not uncommon issues after stroke: up to 75% of patients suffer some form of cognitive impairment, and mood disturbances are common, often presenting as depression or anxiety[12]. In the case of TBI, patients who remain in post-traumatic amnesia are often agitated or confused, and may be considered to be in a state resembling delirium[13] and thus could benefit from strategies commonly used to care for delirious patients, such as the establishment of a quiet and consistent ward environment, and continuity of staff care where possible. It is feasible that distress caused by inadequate management of cognitive and emotional states in the acute setting after neurological injury has some effect on the patient's rehabilitation potential in the short and long term, but no relevant literature could be found that investigates this possibility. It would be interesting to examine whether any such effects might also interact with the demonstrated association between delayed admission to rehabilitation and eventual rehabilitation outcomes.

Conclusions

This essay has attempted to explore some of the issues arising from a prolonged stay in the acute hospital setting while waiting for a specialist neuro-rehabilitation unit bed. These issues were brought to life for me by patient L, who I was privileged to follow as she made this transition after a five-week delay. In choosing to focus on the issues from the patient's perspective, I have not given any consideration to the

implications of delayed admissions for healthcare service delivery, which might pose a rather different set of problems. For example, provision of intensive rehabilitation in the acute setting during the wait for a place in a specialist neuro-rehabilitation unit could lead to functional improvements by the time such a place becomes available, compared to the functional level at which the patient was assessed when they were accepted to the unit. If patients arrive for specialist rehabilitation with a higher level of functioning than the unit is intended to cater for, this has implications for the future planning and resourcing of rehabilitation units.[4]

That said, there are some straightforward implications for healthcare services that follow from the above discussion of delayed access to rehabilitation and lack of continuity of care. Careful consideration needs to be given to the experience of patients who no longer require acute care but who do not yet have access to a place in a specialist inpatient rehabilitation unit. Integrated care pathways for stroke, incorporating dedicated stroke units, have helped to achieve a consistent rehabilitation focus for this patient group, but provision is less streamlined for patients with other neurological injuries (TBI in particular). A model that provides dedicated neuro-rehabilitation beds for such patients within the acute setting could help to avoid the situation like that of patient L, who did not appear to entirely 'belong' anywhere during her wait for a rehabilitation bed.

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