Accessing Rehabilitation after Stroke---A Guessing Game?

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Abstract

Aim: to explore the use, meaning and value of the term 'rehabilitation potential'.

Method:

The authors of this commentary met to discuss concerns relating to the pressure on health service staff created by reduced length of stay in acute settings of those who have suffered a stroke and the need to determine the potential of a patient for rehabilitation in order to inform discharge arrangements. Points raised at this meeting were shared with an email group who over a 12 month period contributed to this paper.

Results: The group agreed that:

- Given that there is very limited evidence to guide judgements regarding rehabilitation potential following stroke at an early stage the need for rehabilitation needs to be reviewed on a regular basis over a long period and that this needs to be reflected in clinical guidelines.
- Rehabilitation needs to be available in a broad range of care settings, in order that discharge from hospital is not equated with a lack of rehabilitation potential.
- Research related to rehabilitation potential needs to be conducted. This should examine influences of decision-making and and local policy on rehabilitation potential.
- The economic benefits of rehabilitation needs further exploration.
- Assessment of rehabilitation potential should be made more explicit and supported by appropriate evidence.

Conclusion:
Whilst further research is required to assist in determining the right time for people to benefit from formal rehabilitation this gives the impression that one dose of rehabilitation at a specific time will meet all needs. It is likely that a rehabilitation pathway identifying features required in the early stages following stroke as well as that required over many years in order to prevent readmission, maintain fitness and prevent secondary sequelae such as depression and social isolation would be beneficial.

Keywords:
potential for rehabilitation, intervention

Introduction

Stroke is one of the biggest contributors to death and long term disability in Europe and the world [1]. Mortality following a stroke in Europe is high and can vary from 54/100,000 of the population in France to 366/100,000 of the population in Bulgaria [2]. Stroke is also likely to be a common cause of disability in the community and the disability adjusted life years (DALYs) lost as a result of a stroke is estimated to vary between 5 and 20 per 1000 population [1]. In 1990 stroke was fifth in the DALYs league table and in 2010 it has moved up to the third position [3]. The cost of caring for persons who have had a stroke is said to account for nearly 5% of the national health care budgets in developed economies. In the EU stroke can cost the economies € 18.5 billion in direct care costs and € 8.5 billion in indirect costs. Informal care costs (costs that are often borne by the families and not for profit organisations) are expected to be € 11.1 billion [4].

Stroke costs the National Health Service and the economy approximately £3 billion in direct cost in England and £8 billion in indirect costs (i.e. care costs and income loss due to lost productivity and disability)[4]. Commissioning guidance for stroke rehabilitation in London found That National Health Service Primary Care Trusts spent on average £1.7 million annually on stroke rehabilitation services. If this figure was extrapolated to England as a whole it would suggest that £300 million out of the more than £3 billion i.e. less than 10% of what is being spent on stroke care is being spent on rehabilitation.

The increase in the societal and economic impact of strokes can, in part, be attributed to the significant advancements in the medical management of stroke. Primarily, more patients are being kept alive (between 1996 and 2006 death rates following a stroke fell by 33.5%) but the recovery potential in those being kept alive has not concomitantly improved [6,7,8,9]. Many studies have detailed that 80% of recovery in terms of activities of daily living including gait and dexterity is achieved within the first three months post stroke, and that final outcome can be defined at six months post stroke however it is frequently noted
that continued recovery over a longer period is observed in ‘many’ [10,11,12,8,9].

**Predicting Rehabilitation Potential**

Rehabilitation has been variably defined. Wade [13] describes rehabilitation as 'the process of trying to help people who have suffered some impairment to maximise psychological well-being, functional ability and social integration'. The Kings Fund [14] defines it as 'a complex process which enables individuals after impairment by illness or injury to regain as far as possible control over their own lives'. These definitions emphasise the broad nature of rehabilitation which encompasses aims to reduce impairments, facilitate improved activity and independence, encourage regaining autonomy and social participation along with supporting and enhancing wellbeing of the patient and family.

For any individual, the level of recovery (outcome) after the stroke and the time course of recovery are likely to be influenced by a range of factors including:

- The lifestyle, health status and, muscular, cardiovascular and respiratory capacity before the stroke. For example, reduced lung capacity increases the risk of poor outcome after stroke [15, 16].
- The location and the area affected by the stroke [16].
- The time delay between the stroke and admission to a medical unit [17,18,19].
- The type and the timing medical treatment given after the stroke (e.g. thrombolysis) [20, 17].
- The medical complications that arise after the stroke [16].
- The type and intensity of rehabilitation therapies after the stroke [21].
- The family and social support available to a patient [22].
- Home adaptation and/or Assistive technology support available to the patient [22].

Decisions relating to potential to benefit from rehabilitation are often based on simple models that consider a small subset of the above factors. Common measures that are used to guide such decisions include the severity of the stroke, as assessed by standardised assessments such as the Barthel Index [23] or the Functional Independence Measure [24], the site and size of the lesion,
premorbid health and abilities. It is generally agreed that those with the most severe strokes who have additional cognitive deficits, incontinence and passivity may recover to a lesser extent and less quickly [25]. This, however, does not mean that these individuals do not have 'rehabilitation potential', within the context of existing definitions. It is important to remember that the lack of evidence of rehabilitation potential is not the same as evidence of a lack of rehabilitation potential. Whilst clinical features such as: level of consciousness, severity of hemiplegia, incontinence, dysphagia and dysphasia, may indicate the likely outcome of the majority of patients, it has been firmly established that a high percentage do better or worse than predicted [26].

Rehabilitation potential, particularly in the severely disabled stroke patient, is unrelated to the severity of the loss and more related to patient and carer needs and ability to adapt. Furthermore, it is possible that individuals with the most severe strokes and apparently with the least potential to move from being dependent to independent are the very ones who may benefit from very early rehabilitation by experts, who can support and establish approaches and strategies for them and their carers that improve the quality of life and reduce burden [27, 28].

There may be confusion between predicting natural unassisted recovery and predicting responsiveness to targeted rehabilitation. All those involved in stroke care are fully aware of the numbers of individuals who make substantial improvements many months, if not years, after stroke – yet there is no systematic study of this phenomenon.

There is now unambiguous evidence that rehabilitation is essential to facilitate recovery after stroke [20,29,30,31] but this does not tell us exactly who will or will not benefit from rehabilitation or in what way. However, it appears that the right of entry to rehabilitation may be becoming more challenging as decisions regarding access to active rehabilitation services need to be taken more quickly. Sentinel Stroke National Audit Programme (SSNAP) [32] indicates that the mean length of stay in 2001 was 34 days and has reduced to under 20 days with half of patients staying for seven days or less.

The judgement on whether to arrange rehabilitation, its type, intensity and setting, is normally made by the multidisciplinary team. These judgements are inevitably affected by the context in which the clinicians are practising
particularly resource pressures affecting length of stay, and the availability of community support or step-down facilities such as intermediate care and community rehabilitation. There tends to be an ‘all or nothing approach’ to the decision of offering rehabilitation and this appears to be linked to a prediction on whether a patient is likely to ‘benefit' from rehabilitation therapies (i.e. those with rehabilitation potential). A prognostic label of “no rehabilitation potential”, if wrongly attached, can permanently deny access to services which may be of benefit and could be interpreted as ‘doing harm’.

If we accept that rehabilitation has a role in facilitating recovery and community participation then the decision to offer rehabilitation (or not as the case maybe) is a crucial one. If we get this decision right then we have the potential to make significant long term cost savings in both the health and social care sectors, and reduce the burden, economic and otherwise, on individuals, families and society. However, if we get this decision wrong then it is more than likely that the costs associated with the long term care of stroke patients is likely to continue to increase.

The Need for Research to Identify "Rehabilitation Potential"

A Cochrane review [33] considered the evidence associated with comprehensive stroke unit care as compared to more generalised care. They concluded that the components of stroke unit care that improved outcomes are multifactorial and most probably include early mobilisation. These authors subsequently undertook a randomised controlled trial [34] examining the difference in outcomes associated with co-located acute/rehabilitation stroke care with traditionally separated acute/rehabilitation services. Both service styles were found to be equally effective in improving functional independence but co-located services were found to be more efficient and the authors speculate that there is the potential for significantly improved hospital bed utilisation with no patient disadvantage by integrating acute with rehabilitation stroke services and this stimulates an attitude to integrating rehabilitation into hospital care from day one rather than trying to determine whether the individual has potential or not.

However, the National Audit Office’s review of the implementation of the National Stroke Strategy [5] reported that, in 2009, 30% of stroke units providing rehabilitation excluded patients with ‘no rehabilitation potential’, a
practice which the Royal College of Physicians (UK) described as ‘unacceptable’.

The National Sentinel Audit of Stroke (SSNAP)[32] by the Royal College of Physicians demonstrates great variation in provision of rehabilitation. For example, the pressure on acute beds and an explicit requirement to reduce length of stay, has led to rehabilitation becoming synonymous with the concept of ‘safe discharge’, moving away from its broader fundamental principles of increasing independence physically, socially, psychologically and emotionally [13]. An unintended outcome of such an approach is that 10.1% of individuals are being discharged to care homes of which 65% were not previously a care home resident (SSNAP p 82). It is possible that a proportion of these did not have the opportunity to recover sufficiently to have their potential appropriately assessed and are thus likely to be denied rehabilitation which is often unavailable in care homes.

The vagaries of changing clinical and service circumstances is likely to affect the decision making process. For instance, in June 2014 with hospital bed demand levels at ‘moderate’, an 88 year old patient with severe right-sided weakness affecting both upper and lower limbs necessitating wheelchair use and hoist transfer, with global aphasia and poor self-awareness, may be admitted to a post-acute stroke unit for several weeks of in-patient rehabilitation. In November 2014, with bed demand levels at ‘high’, the same patient might experience the result of the decision that rehabilitation potential was low, therefore recommending transfer to an appropriately supportive residential setting, such as a nursing home. Once in a residential setting the chance of receiving stroke specific rehabilitation is low [35].

From a ‘decision research’ perspective, there is no reason why assessing someone for rehabilitation potential is any different to other healthcare judgements [34,35]. Individuals find the task of identifying a “signal” (for example, the “potential for rehabilitation”) in a “noisy” clinical environment difficult. ‘Noise’ in a rehabilitation setting includes the information which is present at the time of judgement but which yields little relevant information for that particular decision. Such noise may include: persuasion by the relatives, lack of other facilities for care, the pleasant (or otherwise) affect of the patient etc. There is poor calibration of judgements made by different clinicians which results in similar circumstances or signs being interpreted in different ways
[37,38,39]. However, there is evidence that some variables are very strong predictors and they can then swamp the model in a way that prevents detecting the subtleties that fully determine the potential for rehabilitation of an individual. Models of prediction of rehabilitation potential have never been fully and properly prospectively tested and existing models can only explain 47% of the variance in recovery after stroke, therefore 53% of the variance remains unaccounted [40].

Although, it is possible that individuals with the most severe strokes and apparently with the least potential to move from being dependent to independent are the very ones who may benefit from very early intensive rehabilitation, however, the evidence of benefit is not unambiguous. There is sufficient evidence that even chronic stroke patients may benefit from an additional package of rehabilitation therapy [41,42] and that natural unassisted recovery may have significant confounding effect when we try to model and predict responsiveness to targeted rehabilitation. In a randomised controlled trial to evaluate the effect of surface neuromuscular electrical stimulation to the shoulder following acute stroke it was clear that the recovery patterns fell into four groups: (a) Patients who are recovering up to the three month period and then continuing to improve or plateau; (b) Patients who recover up to three months and then deteriorate; (c) Patients who start recovery only after the 3-month period; (d) Patients who showed no improvement. [43] [See figure 1 below].

-Figure 1 about here-

In an ideal world one would want to ensure that any rehabilitation offered to a patient is offered at a time (and of a quantity/quality) that would be maximally beneficial to that patient.

This would suggest that there is an argument that specific rehabilitation for some should be deferred rather than an early decision being made that rehabilitation is inappropriate. Furthermore, rehabilitation even if the patient shows little or no immediate improvement may assist in improving insight, and mood, leading to prevention of secondary health and well-being problems and facilitating more engagement with activities and later purposeful rehabilitation.
The initial neurological and psychological shock of the stroke to the patient and the emotional impact on the family may indicate that offering certain types of rehabilitation at an early stage may be inappropriate. But that does not imply that there will never be any rehabilitation potential in the future. The question shifts away from ‘does this person have rehabilitation potential’ to ‘what type of rehabilitation is indicated, at what intensity, by whom, where and when’.

**Conclusion**

The concept of ‘rehabilitation potential’ is imprecise, inadequately defined and influenced by the non clinical context. The lack of explicit tools/algorithms or procedures to underpin decisions on ‘potential’ leads to a tension between what health care professionals may wish to endeavour and resource constraints. There is, therefore, a need for research to explore the effects of clinical decision making and local/national policy on recovery after stroke.

There is an argument that the ‘rehabilitation potential’ of stroke patients should not only be considered early on but needs to be reviewed on a regular basis over many months, if not years. Those who may not benefit from early intervention may well benefit at a later stage. Furthermore, preventing readmission, and, secondary health and psychological sequelae is an important consideration.

All patients should have access to a broad range of interventions, physical, practical, emotional, cognitive, psychosocial etc which should be incorporated into the rehabilitation pathway and available as the needs and potential of the patient are likely to change over time. Integrating rehabilitation in the acute phase with that required later and embedding this within a community setting using the broad range of facilities available, not necessarily health-related, in such would allow greater flexibility and continued rehabilitation.

**Declarations of interest.**

The views expressed in this article are those of the authors and not necessarily those of the NHS, NIHR or the Department of Health

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