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What is Rehabilitation Potential? Development of a theoretical model through the accounts of Health Care Professionals in stroke rehabilitation services.

Running title: what is rehabilitation potential?

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Introduction

Multi-disciplinary team members predict each patient's rehabilitation potential to maximise best use of resources. A lack of underpinning theory about rehabilitation potential makes it difficult to apply this concept in clinical practice. This study theorises about rehabilitation potential drawing on everyday decision-making by Health Care Professionals (HCPs) working in stroke rehabilitation services.

Method

A clinical scenario, checked for face validity, was used in two focus groups to explore meaning and practice around rehabilitation potential. Participants were 12 HCPs working across the stroke pathway. Groups were co-facilitated, audio-recorded and fully transcribed. Analysis paid attention to data grounded in first-hand experience, convergence within and across groups, and constructed a conceptual overview of HCPs' judgements about rehabilitation potential.

Results

Rehabilitation potential is predicted by observations of 'carry-over' and functional gain, and managed differently across recovery trajectories. HCPs' responses to rehabilitation potential judgements include prioritising workload, working around the system, and balancing optimism and realism. Impacts for patients are streaming of rehabilitation intensity, rationing access to rehabilitation, and a shifting emphasis between management and active rehabilitation. For staff, the emotional burden of judging rehabilitation potential is significant. Current service organisation restricts opportunities for feedback on the accuracy of previous judgements.

Conclusion

Patients should have the opportunity to demonstrate rehabilitation potential by participation in therapy. As therapy resources are limited and responses to therapy may be context-dependent, early decisions about a lack of potential should not limit longer-term opportunities for rehabilitation. Services should develop strategies to enhance the quality of judgments through feedback to HCPs of longer-term patient outcomes.

Key words: rehabilitation potential, stroke rehabilitation, decision-making, predictors, resource allocation, service delivery, qualitative.

Introduction

Health Care Professionals' daily clinical work requires judgments to be made about the potential for patients to benefit from rehabilitation interventions. At an individual patient level, judgements about rehabilitation potential will determine when rehabilitation begins; the intensity of rehabilitation that is required and can be tolerated for rehabilitation to be effective; and at what point further rehabilitation intervention would fail to deliver meaningful outcomes for patients. As rehabilitation services compete for funding in a context of growing demand and limited capacity, it is inevitable that HCPs are required to make judgments about which patients have the potential to benefit from rehabilitation. Those patients thought not to have rehabilitation potential may be tracked more rapidly than others to care homes, or may have active rehabilitation withdrawn, either in the hospital or community.

Whilst quality standards for conditions such as stroke propose a minimum threshold of therapy for all patients within the United Kingdom [1], the international literature demonstrates that demand for therapy outweighs resource availability [2]. In addition, there is some evidence that patients may benefit from different intensities of rehabilitation provision [3]. The reality is that HCPs will have to continue to allocate therapy resources in ways that balance political, ethical and service perspectives around their perception of a patient's rehabilitation potential [4].

Rehabilitation potential differs from rehabilitation outcome, which is dependent on the availability and receipt of clinically effective interventions. Additionally, individual patients' responses to rehabilitation interventions cannot be easily differentiated from the responses of research populations from which the evidence for these interventions is generated. Consequently, generalisable information that predicts rehabilitation outcome may only partially explain the rehabilitation potential of individual patients. The additional information that HCPs draw on when judging rehabilitation potential is largely unknown.

HCPs may rely on experiential forms of knowledge to guide their judgements and clinical decisions in this area, and integrate these with other forms of knowledge. Understanding the context in which these judgements are made, and what informs them, should improve the quality of the resulting clinical decisions. It is clear that judgements on a lack of potential can be self-prophesying, when they are used in decision-making around the need for long-term care [4], which may fail to provide significant therapeutic opportunities for patients [5]. Prediction models for post-stroke survival [6] and functional recovery [7] over time [8] are available, but, in isolation, these may not be helpful in determining whether an individual patient has achieved their maximum level of attainment across functional and other outcomes. Rehabilitation potential is also closely aligned to the concept of *plateau*, described as a function of patient, therapy and organisational factors [4], where the rate of functional improvement reduces [9].

Although used widely in practice and research, the concept of rehabilitation potential has not been explored in depth, and was adopted as a priority for research by the UK's NIHR Stroke Research Network. By investigating the judgements made by HCPs around rehabilitation potential, this paper aims to address this gap in the scientific literature. Specifically, this study addresses three research objectives:

1. To investigate the meanings that HCPs attach to a concept of 'rehabilitation potential' to HCPs;
2. To explore how these meanings are reflected in HCPs clinical practice; and
3. To examine the influences of judgments about patients' rehabilitation potential on patient and service outcomes.

Methods

The study was approved by the [INSERT NAME] ethics committee. Two focus groups that explored judgements and decisions around rehabilitation potential were conducted with HCPs providing clinical services to people with stroke in England. Rehabilitation teams were contacted by phone and invitation letters circulated by a member of the team inviting staff to participate in a group. Interested staff were provided with additional information and written consent was obtained in advance of the group.

Each focus group was facilitated by up to three researchers: one guiding the discussion to the scenario through a semi-structured discussion schedule, with up to two others posing supplementary questions and completing field notes. Both focus groups were digitally recorded and fully transcribed prior to analysis.

The focus group discussions were structured around a clinical scenario depicting a case history where rehabilitation potential may have been expected to be considered in practice in both acute and longer-term follow-up settings. The use of scenarios is well established in clinical decision-making research [10], and provided an opportunity to uncover HCPs' implicit understandings of rehabilitation potential [11]. Prior to the focus group, the scenario was checked for face validity by four experts in stroke rehabilitation who were members of the Rehabilitation Clinical Studies Group of the UK Stroke Research Network. Members were asked to comment on the plausibility of the scenario, and the degree to which it may generate reflections on rehabilitation potential in clinical practice.

The analytical challenge was to construct a conceptual overview of the judgements made by health care professional staff, including the contextual influences shaping those judgements, and their antecedents and consequences. The process of analysis was based on that proposed by Ritchie and Spencer [12]. Each transcript was read by all members of the research team multiple times to familiarise themselves with the text, and to generate a list of potential codes. The dimensions of potential codes were discussed at a team meeting to generate shared meanings, and to ensure parsimony. Codes were then applied to portions of each transcript with a similar meaning, and tables produced to provide a display of related data within and across both focus groups. These were then explored by all researchers together in a further full-day workshop to generate an initial, linking theoretical framework across the codes and transcripts. This linking framework was generated figuratively and iteratively as a consensus was reached about explanatory relationships across the codes. For example, the initial analysis identified multiple factors that participants perceived to influence rehabilitation potential. Subsequent analysis, and the attention paid to 'visibility' in accounts of the meaning of rehabilitation potential, prompted the specification of these factors into patient-derived mediators, and organisationally-derived factors that 'masked' rehabilitation potential. Although the case scenario was used to drive data collection, particular attention was paid in the analysis to reports of first-hand experiences rather than more general attitudinal perspectives that the case prompted. Field notes were used to inform the analysis by highlighting areas of the discussion where a consensus appeared to emerge, or where disagreement amongst the group was obvious.

Results

As shown in table 1, 12 participants took part in the study representing staff from two in-patient stroke units (six participants) and five community based therapy teams (six participants). Of the community based staff three worked in stroke specific multi-disciplinary services; two in generic, uni-disciplinary services; and one in a neurological-specific service. All participants had clinical roles ranging from entry level to therapy team lead level.

INSERT TABLE 1

The findings are organised around our three questions, and summarised in Figure 1. Exemplary quotations are included to highlight the findings, each with the focus group number and participant's professional role indicated in parentheses.

INSERT FIGURE 1

The meaning of rehabilitation potential

Rehabilitation potential was consistently described as the visible achievement of goals or outcomes over time: *“Are they achieving their goals? That’s what we kind of see as potential to improve, that’s kind of our marker”* (Physiotherapist, FG2). Whilst this position was generally uncontested, there was some discussion about the legitimacy of ‘softer’ outcomes of rehabilitation as markers of rehabilitation potential. These outcomes included environmental interaction and quality of life: *“we can say they’ve got rehab potential, but it’s not going to change their functional outcome... their rehab potential is to be able to stay awake enough to interact with their environment and be hoisted out into a specialist supportive chair... but that’s not going to change their functional outcomes to go home, or 24 hour care”* (Physiotherapist, FG2). Rehabilitation potential, was also defined by observing carry-over, either within or across therapy sessions, for example: *“[a patient’s] ability to attend to what we’re saying and use that information within the session. So, are they transferring it across within the session?”* (Occupational Therapist, FG2).

In this sense, rehabilitation potential emerges through the provision (and potential failure) of therapy. Whilst most of the discussion focused on positive achievement, references were also made to a *“controlled fail...[which could be] quite effective”* (Occupational Therapist FG2) in highlighting a lack of potential, particularly where patients have little insight into the rehabilitation challenges they face.

HCPs’ behaviours around rehabilitation potential

There were three key behaviours which appeared to be characteristic of HCPs’ use of rehabilitation potential in clinical practice: prioritising, working the system, and balancing realism and optimism with others.

Prioritising

Within the context of service pressures outlined earlier, HCPs reported *“prioritising therapy with people who are improving, who have got significant carry-over, they are the ones that obviously... got rehab potential”* (Occupational Therapist FG2). Participants likened the prioritising work to that of a balancing act: *“So it’s that balance of trying to accept there’s people waiting to come for rehab who are at the early stages of neuroplasticity... but then we’ve got people who have probably reached their level of potential with us”* (Speech and Language Therapist FG2).

Working the system

As indicated earlier, the data demonstrate an awareness of limitations in the configuration and delivery of the stroke service model. There were instances in the data where HCPs were able to draw on their knowledge of how things work to (from their perspective) advocate for patients who they felt were disadvantaged: *“reaching a plateau with this patient... we wanted to get her home as soon as possible. But because of issues in the community [housing and adaptations] we ended up keeping her. We knew with the 45 minute kind of thing... she would actually be seen more with us”* (Physiotherapist FG2).

Balancing realism and optimism

Discussions identified that a considerable amount of HCPs' energies were spent balancing different perspectives across staff groups; between staff, patients and families; and between service pressures and individual patient's needs. This was usually couched in terms of balancing realism and optimism across different viewpoints: *"they (family members) come here with expectations that things are going to massively change and we're almost having to unpick that"* (Occupational Therapist FG2). Uncertainty, usually explained from the experience of unexpected recovery when no rehabilitation potential had been observed, meant that HCPs didn't *"want to be doom and gloom"* (Speech and Language Therapist FG1). Prediction around rehabilitation potential was generally described from an intuitive perspective, with limited scope for research to address its complexity. As such, a common strategy used to address this uncertainty referred to *"sowing the seeds quite early on in our meetings"* (Physiotherapist FG2) with, more usually, families around potential outcome scenarios. This was felt to be particularly important where HCPs felt that other members of the multi-disciplinary team had been unrealistic: *"where doctors have spoken to families and say 'Just wait until the HCPs start working!' and you're sat there going well we're going to do as best you can... but how realistic are [the doctors]?"* (Occupational Therapist FG2).

There was a sense across both groups that HCPs' judgements and practical work around rehabilitation potential were integrated around three contextual dimensions of a patient's recovery: time, the recovery trajectory, and the setting. There was a general agreement about the need for flexibility in timing rehabilitation, and consequently the observation of rehabilitation impact, in different care settings. There was some disagreement across views about trends in stroke rehabilitation, and specifically questions about the merits of routine early and intensive intervention when *"they've got other needs which are more burning than us doing rehab"* (Occupational Therapist FG1). There was a sense that, through the ways that the contribution to stroke care was organised, HCPs often had only limited capacity to affect change in the acute stroke service, and for rehabilitation potential to be visible, specifically within the context of a short length of stay in acute stroke. Participants observed that *"sometimes it takes people a couple of months"* (Occupational Therapist FG2) for rehabilitation potential to emerge from a period of no recovery, or where the patient had *"plateaued"*. For example, whilst getting home can be an over-riding aim in the early days after stroke, the reality of getting home can motivate around rehabilitation: *"once they get home and realise what they can and can't do... then it's hang on a minute. Where's my therapy?"* (Occupational Therapist FG1). Highlighting that plateaus in recovery reflected an interaction between intervention, time and place, participants outlined the challenge of *"broaching that subject where the patient has plateaued, we think... the best thing to do is to work from home... [as patients can] get significantly better because things are much more in context to their world and lifestyle"* (Occupational Therapist FG2).

The consequences of rehabilitation potential judgements

Addressing rehabilitation potential resulted in the following possible impacts for patients: allocation to different rehabilitation streams; the rationing of rehabilitation; and shifting the emphasis of intervention between rehabilitation and more general aspects of patient management.

Rehabilitation potential was used to 'stream' patients around rehabilitation intensity, although this was linked to effective management of therapy resources and professional responsibility. Streaming was evident within day to day work: *"we make sure that somebody in the team is going to get the more low level patients out and seated in a good position to build up tolerance out of bed... [providing resource for] somebody else who potentially is going home in a couple of weeks who we could get better"* (Rehabilitation Assistant FG2). At an individual patient level, where HCPs felt patients had

limited capacity to carry-over, the emphasis of therapy was on maintenance rather than active rehabilitation. References were also made to the need for streaming within the stroke service model: *“sometimes people just need time. I think people are very quickly labelled as no rehab potential whereas maybe they just need a slower rehab stream”* (Physiotherapist FG1). Whilst streaming was generally referred to in terms of individual patient’s problems and therapy needs, there was evidence of variation in service delivery, or rationing of therapy, explained in terms of service capacity: *“we will give them the opportunity of what our service level agreement allows us to do... it’s trying to strike a balance... that person is doing that well, and we’ve got the next person coming along who’s doing a little better”* (Occupational Therapist FG2). This discourse was intertwined with sentiments about a duty of care where attempts were made to see patients with little *“rehab potential [once or twice a week] to make sure the patient has not developed pain... contractures.. or have less a range of movements”* (Physiotherapist FG2).

An important consequence for HCPs of work around rehabilitation potential could be characterised as emotional labour. This was particularly evident in discussion around the management of demand and therapy resources. Prioritisation was associated with feelings like being *“torn sometimes, then you feel bad because you’ve not had a chance to see some of the low priority patients”* (Rehabilitation Assistant FG2).

The mediators of rehabilitation potential

A consistent thread within the data related to the multiple influences of different factors on rehabilitation potential. From a biomedical perspective, the type of stroke and its co-morbid nature, played a significant in mediating judgements about rehabilitation potential:

“ haemorrhages tend to recover quite spontaneously... people will have different rehab potential depending on the stroke that they’ve had” (Speech Therapist FG2)

“If we saw in the past medical history they had a background of dementia and their baseline was quite poor, then we think their potential for carry-over in a rehab environment isn’t great” (Occupational Therapist FG2)

Both groups also articulated that key components of rehabilitation potential were the psychological factors such as mood, motivation and attention which both demonstrated, and potentially limited, rehabilitation potential. There was a sense in the data that instead of drawing on motivation in a superficial way, HCPs viewed this motivation within the context of deeper motivations across the lifespan which could provoke frustration and anger on the part of patients. Motivation was associated with cognitive factors such as insight, pre-stroke memory skills, mental capacity, and attentional skills. A lack of meaningful information about how patients were before their stroke, even to the degree of *“the way they have sat and held themselves, and what they have done, and the choices they have made”* (Occupational Therapist FG2) was reported to make decisions about rehabilitation potential difficult. These mediators were also set within the context of the rapport developed between the patient and HCP. Other social factors mediating rehabilitation, and the potential for patients to progress, were family support and expectations: *“Some families are really co-operative... that can influence how quickly someone can be discharged and where someone is discharged to”* (Occupational Therapist FG2). Family involvement also presented new opportunities in addressing gaps in resources: *“with our current resource level you need the family to get the best out of them anyway”* (Occupational Therapist FG1).

Masking rehabilitation

The data also highlighted service factors that, to some degree, masked the visibility of rehabilitation potential, including patient acuity, length of stay, and service model changes. Both groups highlighted the impact of service commissioning in changing the nature of therapy provision: *“we’re limited a bit more with the service level agreement that we’ve got of three times a week”* (Speech Therapist FG2). However this business context also required staff to *“justify what we are doing and it makes us clinically reason every step of the journey”* (Physiotherapist FG2).

Shifts in the design of the service model, with greater attention to intensive intervention following early and rapid admission to hospital for acute stroke patients, were associated by participants with increasing patient acuity, and increasing workloads. Participants reported that despite these changes, and quite substantial service re-design, the skill mix had been consistent. In contrast however, the development of political imperatives around targets for the quantity of therapy being provided prompted creative behaviour and resourcefulness around how therapy services were organised. Examples included the use of group-based approaches to delivering therapy and better team-working.

More subtle masks of rehabilitation potential were aspects of clinical geography where the nature of the clinical environment (when compared to home) made it difficult to ‘see’ rehabilitation potential. Participants reported that it was typical for patients to respond better in their home environment which may provide more opportunities for patients to be active.

The importance of providing a structure for members of the multi-disciplinary team to contribute to action on rehabilitation potential, and specifically a *“consistency in approach and discipline”* (Speech Therapist FG2) was evident. Participants spoke of inconsistency emerging from a reliance on different sources of information, for example diagnostic imaging rather than the observation, resulting in mixed messages about rehabilitation potential. A considerable discourse focused on pressures on different professional groups to ensure a timely transfer of care from hospital to home or other long-term placement. In consequence, there was a concern that the over-riding focus of multi-disciplinary meetings could be on *“getting people out, expected date of discharge”* (Occupational Therapist FG1), which diluted discussions about rehabilitation potential issues.

The observation of rehabilitation potential was set within a context of a broad range of information sources around a patient’s functional activity. Each source provided different opportunities to ‘see’ rehabilitation potential with varying degrees of utility. These included formal, structured assessment and more embedded on-going observation of patients’ progress: *“you start thinking about it on your initial assessment, because that deems whether someone goes onto the rehab ward or not... It is reviewed weekly... with an MDT... and would monitor it”* (Physiotherapist FG2) through on-going *“observation of the client doing functional things”* (Occupational Therapist FG1).

Across both groups, assessment tools such as the Barthel Index were deemed insensitive to more subtle changes associated with potential, such as greater interaction with the environment. Some reported that the use of measures could increase the visibility of patients’ progress, and therefore rehabilitation potential. Others suggested that these *“assessments were used to support our qualitative data”* or judgments of potential derived from unstructured observation (Occupational Therapist FG2).

Whilst cognitive assessments were reported as helpful, the information they provided was couched more in terms of planning for rehabilitation rather than indicating rehabilitation potential: *“cognitive measures... are not used to measure rehab potential...[rather] an idea of how impaired [patients were]”* (Occupational Therapist FG2). This reflected a general unease that emerged at times in group discussions, particularly around it being *“difficult to put people in such general boxes, but that’s something they do use on the ward”* (Speech Therapist FG2).

Learning about rehabilitation potential

As indicated earlier, the use of different information sources, including HCPs' previous experience, to guide judgements about rehabilitation potential were clearly evident in the data. However participants also reflected on the quality of this experiential learning, which was felt to be limited: *"I don't always know what happens to my patients and whether they do actually get walking again... I never see the end product"* (Physiotherapist FG2). But *"sometimes in passing you hear about patients because of your own relationships with the HCPs you work with in different areas"* (Occupational Therapist FG2) which can *"inform your practice next time"* (Occupational Therapist FG1).

Discussion

From the perspective of HCPs, rehabilitation potential appears to be a concept that is defined by the actions of patients, specifically in relation to the carry-over of therapy within and across therapy sessions, and the achievement of goals. Information from functional assessment is melded with other forms of tacit and experiential knowledge to guide the work of HCPs around rehabilitation potential. Importantly, the data demonstrated a wide range of features of the stroke rehabilitation service and setting which were thought to mask rehabilitation potential, including service pressures and a lack of an inter-disciplinary approach to rehabilitation potential. The early stages of stroke recovery were reflected in discussions about the need to ensure that patients have the opportunity to demonstrate rehabilitation potential by participation in therapy, that limited therapy resources need to be managed effectively, and that, as there may be limited scope to affect change in patient outcome, decisions about lack of potential do not limit longer-term opportunities for rehabilitation.

The work of HCPs in this area can be characterised as prioritising, working through the system, and balancing realism and optimism, and is shaped by both the characteristics of individual patients' recovery and organisational contextual conditions. The data highlight a range of mood, cognitive and co-morbid issues that affected engagement in rehabilitation, and consequently the evaluation of rehabilitation potential. The complexity and specificity of judgements is an important aspect of the implementation context in this area of rehabilitation practice, and indicates that introducing new practices, including the use of prognostic models of rehabilitation potential, will be equally complex [13].

In the absence of strong prognostic models for rehabilitation potential, these data suggest that, as far as organisational policies and contracts for service provision allow, patients need to be provided with opportunities to engage in rehabilitation that allow potential to be observed. Rather unexpectedly HCPs' judgements of rehabilitation potential appear to depend far more on responsiveness to offering rehabilitation (i.e. outcomes) rather than to predictor variables prior to starting rehabilitation. Managing these opportunities in situations where HCPs' saw limited potential and little insight from the patient or family requires considerable sensitivity and professional judgement. Balancing therapy resources and rehabilitation potential across groups of patients provided a framework which allowed HCPs to shift the emphasis from rehabilitation to essentially the prevention of harm with patients with limited potential. The data indicate HCPs perceived a strong duty of care to these patients, although there were limited data on how on-going review was sustained.

Health policy in the UK is seeking to standardise the minimum provision of therapy for stroke patients, at least whilst patients are benefitting from rehabilitation. Although not a study of the impacts of rehabilitation per se, the findings indicate some degree of tension around the legitimacy of functional and participation outcomes in guiding judgements around rehabilitation per se. The data suggest that rehabilitation potential may, for some patients, be specific to time and place, requiring flexible

approaches that allow for this to inform individual rehabilitation programmes. Changing the environmental context of patients who are in plateau appears to be important, but the mechanisms through which this produces further change for patients are unclear.

The findings reaffirm the importance of HCPs' emotional resilience in this demanding area of stroke rehabilitation practice. The development of expertise around rehabilitation potential is linked by HCPs to opportunities to learn from feedback. The organisation of the stroke rehabilitation service model, and HCPs' ways of working, would appear to limit opportunities for improving the quality of clinical decisions. New strategies are warranted that support learning about the quality of HCPs' decisions [14], and that are commensurate with the 'patterning' of experiences around rehabilitation potential that participants discussed.

The sampling of HCPs from a small number of services that were geographically close may limit the transferability of the theoretical model, which should be explored in other stroke services and with HCPs working with other patient groups. Similarly 50% of the sample was from one health professional group (occupational therapy) and the findings cannot be assumed to reflect the decision-making judgements of other groups who play a major role in rehabilitation, including medical and nursing staff. Whilst the data are generated from a fictional scenario, we ensured this had face validity, and believe this generated discussions that were much closer to the reality of clinical practice around rehabilitation potential.

[4006 words]

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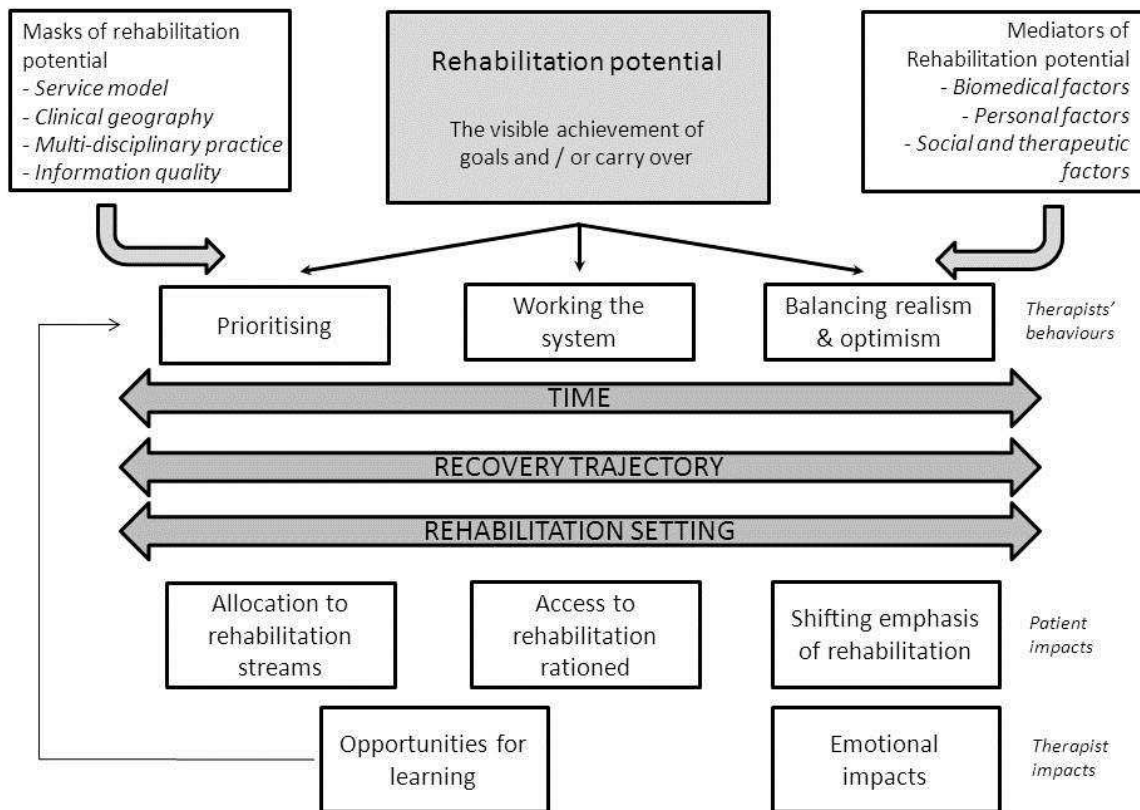


Figure 1. A theoretical model of rehabilitation potential.

Participant Attribute	
Professional Background	
<i>Occupational Therapy</i>	6
<i>Physiotherapy</i>	1
<i>Speech and language Therapy</i>	4
<i>Rehabilitation Assistant</i>	1
NHS Banding ¹	
<i>Level 4</i>	1
<i>Level 5</i>	1
<i>Level 6</i>	3
<i>Level 7</i>	6
Gender	
<i>Female</i>	11
<i>Male</i>	1
Years qualified (<i>mean and range</i>) ¹	9 years 10 months (3 years 6 months – 16 years)

Table 1. Participant Profile

¹ One participant did not provide this data

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