What is rehabilitation?

An empirical investigation leading to an evidence-based description.

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Summary.

Background.

There is no agreement about or understanding of what rehabilitation is; those who pay for it, those who provide it, and those who receive it all have different interpretations. Further, within each group, there will a variety of opinions. Definitions based on authority or on theory also vary and do not give a clear description of what someone buying, providing or receiving rehabilitation can actually expect.

Method:

This editorial extracts information from systematic reviews that find rehabilitation to be effective, to discover the key features and to develop an empirical definition.

Findings:

The evidence shows that rehabilitation may benefit any person with a longer-lasting disability, arising from any cause, may do so at any stage of the illness, at any age, and may be delivered in any setting. Effective rehabilitation depends on an expert multi-disciplinary team, working within the biopsychosocial model of illness, and working collaboratively towards agreed goals. The effective general interventions include exercise, practice of tasks, education of and self-management by the patient, and psychosocial support. In addition, a huge range of other interventions may be needed, making rehabilitation an extremely complex process; specific actions must be tailored to the needs, goals and wishes of the individual patient, but the consequences of any action are unpredictable, and may not even be those anticipated.

Conclusion:

Effective rehabilitation is a person-centred process, with treatment tailored to the individual patient's needs and, importantly, personalised monitoring of changes associated with intervention, with further changes in goals and actions if needed.

Key words:

Rehabilitation description, content, process, therapy, person-centred

Introduction.

What constitutes rehabilitation? Physiotherapy? Exercises? Something you receive 'to get you better'? Many healthcare staff, when referring someone to rehabilitation, have little idea, maybe saying 'they'll sort out your problems for you', or sometimes 'they'll work you really hard.'

Commissioners, similarly, rarely understand what they are paying for; at most they expect a certain number of contact hours between a patient and a therapist and/or setting goals. Patients do not know what to expect.

Searching dictionaries or the internet does not help much, because the answers are imprecise and lack detail. Commissioners (for example) still would not know what they are paying for, how to assess its quality, or how to quantify it if depending upon published definitions, such as one in a recent commissioning guide [1] (Box one), or others. [2][3][4] Most definitions are not based on evidence.

Box one

An empirical investigation into the phenomenon of rehabilitation might clarify the matter. This editorial reviews studies reporting that rehabilitation has a beneficial effect, and asks: what aspects of the intervention being studied, rehabilitation, are common between the various studies investigating successful rehabilitation?

This approach is not new. It was used to investigate the nature of 'stroke unit rehabilitation' in 2002, [5] and the 2013 review [6] stated:

"In summary, organised inpatient (stroke unit) care was characterised by: (1) co-ordinated multidisciplinary rehabilitation, (2) staff with a specialist interest in stroke or rehabilitation, (3) routine involvement of carers in the rehabilitation process and (4) regular programmes of education and training."

This editorial, based on systematic reviews and larger individual trials, identifies the features of rehabilitation found in studies showing that patients benefit. Its aim is to discover the main characteristics of effective 'rehabilitation'. The results are presented in three domains:

- Context; who may benefit, and does location matter?
- Process; what are the common features of the process?
- Interventions; what interventions are used?

It develops an evidence-based description of effective rehabilitation.

CONTEXT.

This part investigates whether the benefits of rehabilitation are restricted to specific patient groups, or to delivery in specific locations.

What conditions are associated with benefit?

Systematic reviews have considered rehabilitation involving patients covering a large range of conditions, diseases, and ages, and in almost all groups a positive effect is shown. Patients can be helped by rehabilitation if they have:

- pulmonary and respiratory conditions; [7][8][9]
- cardiac [10][11] conditions;
- neurological conditions such as multiple sclerosis, [12][13[14] stroke, [6] motor neurone disease [15] and other conditions; [16][17]
- musculo-skeletal disorders such as fractures, [18][19] hip and knee arthroplasty, [20] and sub-acute or chronic back pain; [21][22]
- malignancies [23][24]

The common feature among the wide variety of disease disorders listed above is that the patient has a continuing disability, often with several or many factors contributing to the situation.

The only reasonable conclusion must be that rehabilitation, whatever it is, is likely to benefit anyone with persistent disability associated with an illness, regardless of the underlying disease or disorder.

Is rehabilitation effective anywhere?

Rehabilitation has been found effective in most settings:

- probably in intensive care units (there are many reviews, with contrasting findings)
 [25][26][27][28];
- specialist rehabilitation inpatient wards [6];
- out-patient and day-hospital settings; [29][30]
- nursing homes; [31] and
- at home. [32][33][34]

It is specifically important to note that rehabilitation out of hospital, after discharge, is effective. [32][35]

Although the strength of the evidence varies, there seem little doubt that rehabilitation can have a beneficial effect wherever it is delivered. Direct comparisons between different setting have rarely been studied,

Does stage or prognosis of disease affect effectiveness?

Categorisation of disabling disorders by prognosis and stage is difficult, and the categories suggested are not as distinct as they appear. Moreover, the effects of development (in children)

and aging (in older adults) lead to changes in disability and/or rehabilitation needs.

Nonetheless, there is evidence that rehabilitation is beneficial in:

- the acute phase of sudden onset disorders; stroke, [6] acute episodes of coronary artery disease, [10] hip fracture, [18] traumatic brain injury [16]
 - including those where there is no 'natural recovery', such as spinal cord injury where rehabilitation has transformed life expectancy and social functioning.
 [36][37]
- the later, more stable phases of acute onset disorders: stroke [38]
- diseases that have a slow or fluctuant onset and are progressive to a greater or lesser degree: multiple sclerosis,[12][13][14] osteoarthritis, [39] chronic back pain [21]
- diseases that are more inexorably progressive: Parkinson's disease, [17] Alzheimer's disease [40][41]

One may conclude that rehabilitation is likely to be beneficial to a person with disability at any stage of their illness and whatever the nature of their prognosis, including when receiving palliative care: rehabilitation can benefit people with advanced cancer. [42]

Does age limit effectiveness?

There are few trials of rehabilitation (in contrast to trials on specific interventions) involving children, and no reviews were identified. The studies already referred to have included people of all ages from teenagers through to the very old and frail. There is no reason to doubt that rehabilitation is effective at any age, though there is little evidence for children.

PROCESS.

The second part of this review investigates what features of the process are common across the studies showing benefit.

Using the biopsychosocial model of illness.

The use of a biopsychosocial framework [43] is mentioned or implied in almost all reviews and articles. This characteristic is inextricably intertwined with multi-disciplinary teamwork, [44] because any process based on the biopsychosocial model necessarily considers a wide range of factors, requiring input from several different professions. Conversely, any team covering the range of factors in the model necessarily uses a single framework for analysis and communication.

The use of this model [43] is perhaps the defining characteristic of rehabilitation, and distinguishes it from most other medical specialist services. Other healthcare services using the biopsychosocial model, to a greater or lesser extent, are psychiatry, including learning disability and liaison psychiatry services; palliative care; chronic pain services; geriatrics; and probably community paediatrics.

Practicing multidisciplinary teamwork.

In almost all the studies and reviews of rehabilitation, the involvement of a multi-disciplinary team [44] is mentioned explicitly or, if not, it is implied. The important features associated with multi-disciplinary teamwork are also expanded upon in the stroke rehabilitation reviews. [5][6]

The need for and characteristics of multi-disciplinary teams has been reviewed recently. [44]

Studies suggest that, in healthcare, teamwork is generally associated with a better outcome, [45]

and an observational study on stroke rehabilitation teams [46] found a relationship between better outcome and three team features:

- being oriented towards achieving tasks
- extent of order and organisation
- use of good quality information

Another study on stroke rehabilitation teams [47] found that effectiveness improved as the quality of team meetings improved in terms of:

- communication,
- coordination,
- contributions being equal,
- mutual support,
- commitment of members to team goals, and
- cohesion (team spirit).

The evidence thus strongly suggests that successful rehabilitation depends upon a multidisciplinary team being involved. It is important to stress that a team is not just a collection of people who happen to be working with a specific patient; a team works together with each other over time and with many patients. [44]

It is also important to recognise that the team must have specialist expertise (knowledge and skills) in the problems that they see. In the case of stroke unit rehabilitation this was related to stroke, [5][6] but in other setting it might be a condition, such as chronic pain or spinal cord injury, or a particular intervention such as assistive technology, or some other particular aspect of rehabilitation. Acquiring and maintaining specialist expertise requires continuing

multidisciplinary education and training (i.e. training in areas outside each person's limited professional field). [5][6]

Other important characteristics associated with effective teamwork [44] include:

- having regular team meetings, both
 - o about individual patients, and
 - about team functioning and processes
- using the setting of goals to:
 - o motivate the patient and team members
 - o ensure co-ordination of actions between different people and over time
- working collaboratively to
 - o support each other's interventions
 - o share information, including specific knowledge and skills

Using structured protocols.

Just as the evolution of the biomedical model of illness led to a very standardised way of approaching the biomedical aspects of illness, with great success, so a structured careful, almost obsessional approach arising from considering all factors within the biopsychosocial model of illness is an important aspect rehabilitation's success. The team's use of structured approaches to common problems, be that assessing a person's losses and abilities, or reacting to challenging behaviours, or communicating and reporting on clinical matters is part of the 'coordinated approach' identified in stroke services. [5]

The effectiveness of structured protocols is perhaps illustrated most powerfully in the field of spinal cord injury rehabilitation. [36][37] Between 1935 and 1955 the prognosis for someone

with a spinal cord injury was transformed from an early death, secondary to sepsis and renal failure, to returning to community living and employment with a reasonable (but not yet fully normal) life expectancy. This arose in the absence of any treatment for the injury or transformative medical advance relating to the 'complications' that killed people. Using structured protocols may also account for the reduced mortality associated with stroke unit care. [6]

Being person-centred (and family-centred).

Two characteristics of successful stroke rehabilitation were "routine involvement of carers in the rehabilitation process.", [6] and routine provision of "information on stroke disease, rehabilitation, and recovery." to both the patient and the family. [5] Being person-centred is also consistent with both goal-setting and shared decision-making, both processes that are widely advocated although perhaps lacking the evidence needed to make a strong case for them. [48][49][50]

There is a close overlap between being person-centred and rehabilitation. Before discuss it further, we need to consider two groups of interventions, those which:

- are effective and applicable across the majority of rehabilitation services
- are specific to certain conditions.

INTERVENTIONS - 1

The interventions mentioned most often in reviews are: exercise, education and the giving of information, and providing psychosocial support. For example, in cardiac rehabilitation, a recent review identified five core components of an effective programme. [51] Three of the components are applicable to almost all conditions – exercise training, psychosocial management, and patient education. Two could be considered more specific to cardiac disease,

nutritional counselling and risk factor modification, but alternatively they could be considered specific aspects of patient education. One study suggested psychosocial support was an essential part of respiratory rehabilitation, [52] but there is little further evidence as to the meaning or content of 'psychosocial support'. Exercise and education will be discussed further.

Exercise

Exercise, as used in rehabilitation research, carries two meanings. The first concerns undertaking muscular, physical activities that are associated with increased energy consumption and cardio-respiratory work. The second concerns the performance of a specified activity, usually practicing it to improve performance. Often the two will coincide, with undertaking the task-related practice of walking being a good example.

The benefits of 'exercise' as reported in studies may therefore arise from:

- practicing a functional activity, by repeatedly performing it, and
- undertaking more muscular work, increasing cardio-respiratory work.

There is strong evidence supporting task-oriented and task-specific training after stroke, [53] with the majority of the benefit being found in improved performance of the specific task. There is probably a dose-response relationship, [54][55] but in practice the extra amount of direct therapy time needed to make a difference is too large to be feasible. [56] The practice of the activity, rather than direct therapy input, is probably the main factor leading to benefit. The general principle of task-oriented training (i.e. practicing a functional activity) applies across all rehabilitation, because it is a principle underlying learning.

There is also reasonable evidence supporting the benefits associated with exercise that increases cardio-respiratory work. The benefits not only include better cardio-respiratory function, [8][9][10][11] but extend well beyond cardio-respiratory fitness. [10][11][39][57] Exercise may help patients with chronic fatigue, [58] low back pain, [59] osteoarthritis of hip or knee, [39] ankle sprains, [60] cardiac problems, [10] chronic obstructive pulmonary disease, [8] and many more conditions, often "with or without education and/or psychological support". [8]

Education, and self-management.

The specific effect of education is not often studied separately. One review suggested education improved quality of life in people with cardiac disease. [61]

However, self-management by a patient with a long-term disabling condition depends on education, and there is evidence to support teaching self-management strategies for:

- chronic obstructive pulmonary disease, [62] improving quality of life, reducing hospital admissions, but possibly increasing mortality [63]
- Stroke, improving quality of life [64]
- Fatigue in people with fatigue associated with cancer and its treatment [65][66]

The common components of successful community-based programmes [67] are also mostly achieved through education about:

- The disease, and management of symptoms and medication
- Core self-management skills
- Exercise programme
- Self-relaxation training

In summary, there is good evidence that practicing functional activities and undertaking cardiorespiratory exercise are both important interventions in any rehabilitation service. Education is also an important intervention, although its content is less well established; it probably always includes knowledge about the disease, its causes, prognosis and treatments, and teaching skills in relation to self-management. Education may also cover managing the emotional aspects of the illness. Teaching about prognosis will, importantly, ensure that the expectations of the patient and family are appropriate.

INTERVENTIONS - 2

The range of actions undertaken by a rehabilitation service is dramatically illustrated by the detailed description of the content of a rehabilitation programme to be undertaken in intensive care units, being evaluated in a trial. No fewer than 12 separate components were identified.

[68] Descriptions of other evaluated rehabilitation programmes illustrate the number and variety of actions that constitute a part of the patient's overall rehabilitation. [69][70]

Thus rehabilitation is definitely a complex intervention, one in which cause-effect relationships are difficult to establish, are often non-linear, and often interact (not always beneficially). Table one illustrates its complexity of rehabilitation as assessed using one set of characteristics used to measure the spectrum of complexity. [71]

An interesting example of the difficulty in defining the 'active ingredient' comes from a trial of adding week-end therapy to an inpatient programme. [72] The trial found a small benefit which, at first glance, might be attributed to the extra hour of therapy. However, the associated qualitative study [73] found that "The patient-therapist interaction was more important to the patient than the amount or content of their physiotherapy". More importantly, they reported that "Saturday

therapy changed patients' perceptions of weekends in rehabilitation." so that patients in the experimental group practiced more on Sundays too! The effectiveness was probably secondary to a change in the patient's perception and expectation (of rehabilitation), not giving extra time.

The complexity of rehabilitation leads to a difficulty faced by both service providers and commissioners. There are very many potential actions that might benefit a patient, but often there is either no evidence available about their effectiveness, or the available evidence is weak or unsupportive.

When evidence of benefit is weak, inconclusive or even negative, it does not necessarily mean that the intervention should not be used (unless harm has been demonstrated). First, it may be that a small number of patients respond well, with the rest being unaffected, such that benefit cannot be detected. Second, the intervention may only help as one component of a bundle of care. Bundles of care are common, such as those for reducing infection [74] or errors in surgery [75]. Often the individual components in a bundle have not been tested separately.

CONUNDRUM and SOLUTION

There is, therefore, a conundrum. Rehabilitation as a process is beneficial. Some interventions that are common to all fields of rehabilitation have been identified. But the evidence base for specific interventions in any particular group of patients is weak or absent, with few exceptions.

To resolve this conundrum, the rehabilitation team must, for each patient::

1. use a collection of interventions to meet the patient's specific needs, taking into account all aspects of his or her situation, wishes, values etc; and

2. evaluate the patient's rehabilitation programme on a planned, ongoing basis using simple targeted measures at appropriate intervals.

That rehabilitation should be so specific to the patient follows from the trite but vital observation that every patient is different. In the context of a single drug or an operation set within a biomedical model, these differences may not matter. In rehabilitation, which is set within the biopsychosocial model, it is inevitable that many if not most actions need tailoring to a patient's situation. Therefore no two patients will have exactly the same rehabilitation package, and no two patients will respond in exactly the same, predictable way. Consequently, when evaluating rehabilitation, each patient needs a tailored package of assessments to evaluate and alter the package, the timing of these assessments also being appropriate to the situation. The process should use a few simple measures only, often to include checking for harm (e.g. sedation from a drug used.).

One term used to encompass this approach is person-centred care. This phrase has many meanings. Two reviews illustrate what the phrase encompasses.

One review [76] focused on **the values and attitudes** associated with person-centred care, suggesting it requires an organisational culture with six characteristics:

- respecting the patient's perspective;
- being compassionate;
- recognising the importance of inter-personal relationships both within the patient's social groups and also between the rehabilitation team and the patient;
- prioritising a patient's participation in social and/or meaningful activities;
- recognising the patient's role as a citizen; and

focusing on a patients strengths and abilities.

A second paper [77] focused upon the necessary processes, identifying eight characteristics:

- an individualised set of goals derived from the patient's preferences;
- ongoing review of the goals and planned actions;
- use of an interprofessional team (to include the patient);
- identification of a key-worker as a single point of contact;
- coordination between all people and organisations involved;
- good communication and sharing of information;
- education and training of both healthcare staff, and the patient and family; and
- performance measurement and quality-control using feedback from patients.

The similarities between rehabilitation and person-centred care is obvious, and there is also evidence that care described as person-centred is effective, [78][79] but not always. [80][81]

Last, this person-centred approach has already been recognised in one definition of rehabilitation, adopted by the American Thoracic Society (ATS) and the European Respiratory Society (ERS) [4] in 2013: "Pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors."

CONCLUSIONS.

A definition of rehabilitation derived from the evidence reviewed is given in Box two, and Figure one outlines the process of rehabilitation that follows from it. The important features that characterise effective rehabilitation are:

- Basing the process on the biopsychosocial model of illness;
- Having an expert multidisciplinary team, which uses structured protocols to ensure a consistent, comprehensive approach
- Undertaking a comprehensive (holistic) initial (diagnostic) assessment to achieve a full
 understanding of the patient's situation, both the factors that influence it and the factors
 that may determine interventions;
- Using many different interventions tailored to the particular patient;
- Monitoring the changes arising in association with these interventions, evaluating them against goals, and checking for potential harms.

Commissioners, organisations responsible for the quality of a rehabilitation service provided, and patients considering a rehabilitation service now have an evidence-based set of criteria to measure the quality of a service.

Box two

Figure one

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Table one

Complexity of rehabilitation, based on Wells et al [71]

n	Complexity characteristic	Interventions in rehabilitation
1	Number of components within it	Multiple components, both in processes and in actions
		undertaken
2	Its quantity and/or intensity	Depends entirely upon the patient's specific situation and
		problem(s); no 'standard' dose of any component
3	Ability to specify the components	The component processes need to identify and then solve
		problems defined, but the actions needed cannot be
		specified at the start of rehabilitation
4	Confidence in identification of its	In almost every case, it is impossible to be even partially
	active component	certain about the active component, and it is likely that
		one action influences several factors within the individual
		patient's situation
5	Timing of actions involved	Multiple actions over time, with interdependence and
		often also dependent upon a correct sequence.
6	Number of people involved in its	Usually large, sometimes very large
	delivery	
7	Extent to which responsibility for	Low ability to delineate responsibility, and team members
	intervention can be delineated	and others often share responsibility for actions and goals
8	Number of different (professional)	Large number of different professional groups involved,
	groups involved	often coming from outside the 'core team'

9	Technical/professional skill	Depends upon specialist knowledge and skills in initial
	involved	assessment and analysis, in practical treatment processes
		and in broader psychological and communication spheres
 10	Extent of human interaction	Almost totally dependent upon human interaction; inter-
	needed to deliver it	personal relationships with the patient, family members
		and other involved professionals are all crucial
 11	Number of settings and	May be delivered in many settings consecutively or
	organisations involved	together, and will almost always involve working across
		geographic and organisational boundaries
 12	Degree of patient involvement and	Patient engagement is essential at all times, with the
	participation needed	exception of patients who are unconscious.
 13	Sphere of impact of the actions	The processes and the effects of actions both involve many
		people surrounding the patient
 14	Ability to define and measure	Many important outcomes are difficult to define
	main outcome(s)	precisely, and most are only measurable through patient
		report. E.g. Quality of life, life satisfaction, social
		integration. The patient's own goals may not be
		measurable.

A definition of rehabilitation

From NHS England's guide on commissioning rehabilitation [1]

The goal:

"A modern healthcare system must do more than just stop people dying. It needs to equip them [patients] to live their lives, fulfil their maximum potential and optimise their contribution to family life, their community and society as a whole."

The content:

"Rehabilitation achieves this by focusing on the impact that the health condition, developmental difficulty or disability has on the person's life, rather than focusing just on their diagnosis. It involves working in partnership with the person and those important to them so that they can maximise their potential and independence, and have choice and control over their own lives. It is a philosophy of care that helps to ensure people are included in their communities, employment and education rather than being isolated from the mainstream and pushed through a system with ever-dwindling hopes of leading a fulfilling life."

An evidence-based description of effective rehabilitation

The goal.

To optimise a patient's self-rated quality of life and degree of social integration through optimising independence in activities, minimising pain and distress, and optimising the ability to adapt and respond to changes in circumstances.

Patients and places:

Rehabilitation may

- benefit anyone with a longer-term disabling illness at any stage of that illness;
- be delivered in **any setting**

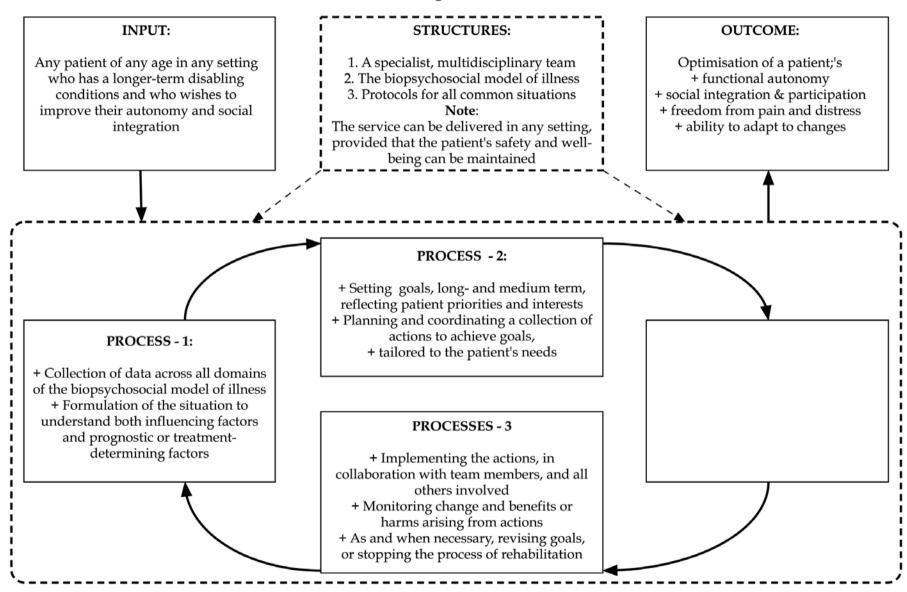
The content.

Rehabilitation:

- Is a problem-solving process, framed in the context of the holistic biopsychosocial model of illness, delivered in a person-centred way, and requiring:
 - o an expert, multi-disciplinary team, setting collaborative team-based goals;
 - a **formulation** of the situation, covering all domains of the biopsychosocial model
 - close, collaborative working across all boundaries, professional,
 organisational and geographic
 - o ongoing **monitoring** of change and effects of interventions

- Will almost always use the following **general approaches** to management
 - o Repeated practice of functional activities
 - o General exercise that increases cardio-respiratory work
 - Education with an emphasis upon self-management
 - o Psycho-social support (not well defined yet)
- and always involves a large number of specific actions tailored to the patient's priorities and specific needs and goals,
 - o covering (if necessary) all domains of the biopsychosocial model of illness
 - being evaluated regularly for their benefits and harms, to determine whether
 they should be continued, changed or abandoned

Figure one



Rehabilitation: who benefits, what structures are needed, what processes occur, and what is the outcome?

