


Concepts of rehabilitation

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Introduction

What are the basic concepts of rehabilitation medicine? In many ways rehabilitation is different from most other medical specialties. It is primarily a process of education of the disabled person so that, ideally, they can cope with family, friends, work, and leisure with as little support as possible. Thus, rehabilitation is a process that centrally involves the disabled person in making plans and setting goals that are important and relevant to their own circumstances. Rehabilitation is not a process that is done *to* the disabled person but it is a process that is done *by* the disabled person with the guidance, support, and help of a wide range of professionals as well as family and friends. Rehabilitation is also a process that goes beyond the rather narrow confines of physical disease and also deals with the psychological consequences of disability as well as the social milieu in which the disabled person has to function. A key factor that differentiates rehabilitation from most of medicine is that it is not a process that can be carried out by medical practitioners alone and of necessity requires the active partnership of a whole range of health and social service professionals. The characteristics of rehabilitation are listed in Box 1.1.

Box 1.1 Characteristics of rehabilitation

- It is an educational process.
- Crucial involvement of the disabled person in programme planning.
- Key involvement of family, friends, and colleagues.
- It is a process that requires clear goals to be set and measured.
- It is a multidisciplinary process.
- It is a process based on the concepts of activity and participation—
 see Impairment, activity, and participation p.4.

Impairment, activity, and participation

Historically, the key principles that lie behind rehabilitation are those that were proposed by the World Health Organization (WHO) in 1980—impairment, disability, and handicap. These old definitions are fundamental to rehabilitation and are shown in Box 1.2. However, whilst these older definitions are of significant historical interest, in 2001 they were replaced by new classifications produced by the WHO. The new definitions are seen in Box 1.3.

Impairment has remained in both these classifications. Impairment is simply a descriptive term that says nothing about consequence. A right hemiparesis, for example, or a left-sided sensory loss, or a homonymous hemianopia are impairments. However, the right hemiparesis can be relatively mild leading to virtually no functional consequence or can be profound leading to complete inability to walk. It is the functional consequence of the impairment that used to be described as the disability and is now described as activity limitation. Rehabilitation goes beyond impairment and looks at the functional context and tries to minimize the functional impact of such impairment. It is, after all, the limitation to activity that matters to the individual and not the impairment. Rehabilitation medicine does not minimize the importance of diagnosis and impairment in an effort to understand the underlying pathophysiology but simply places equal emphasis on the consequent limitation of activity.

Participation is defined as involvement in a life situation. This is broadly equivalent to the old term—handicap. Participation is described as social context. In our example of a right hemiparesis even a relatively mild right-sided weakness can have profound implications for a young man who is a scaffolder or who wanted to go into the armed services, as such occupations would be closed to him or an existing job may be lost. However, an older man who is already retired and whose abilities are restricted by other problems such a difficulty may have limited impact on his lifestyle. The concept of participation does not only deal with the broader physical consequence of an activity limitation but looks at the broader social context. A mild hemiparesis, for example, in a receptionist may not actually prevent that person from undertaking the job and being a good employee. However, the attitude of the employer to the disabled person may cause them to be moved elsewhere or even lose their job. A person who needs to use a wheelchair may be quite capable of undertaking their job but cannot move around the office because it is not wheelchair accessible. Rehabilitation needs to take into account not only the activity limitation but also the particular societal context for that person. Thus rehabilitation strays into the arena of societal attitudes and the physical environment, which are traditionally outside the realm of medicine.

Box 1.2 Historical definitions of the WHO's International Classification of Impairments, Disabilities and Handicaps (1980)

- *Impairment*: any loss or abnormality of psychological, physiological, or anatomical structure or function.
- *Disability*: any restriction or lack of activity resulting from an impairment to perform an activity in the manner or in the range considered normal for people of the same age, sex, and culture.
- *Handicap*: a disadvantage for a given individual resulting from impairment or disability that limits or prevents the fulfilment of a role that would otherwise be normal for that individual.

Box 1.3 International Classification of Functioning, Disability and Health (ICF)

- *Impairment*: loss or abnormality of a body structure or of a physiological or psychological function.
- *Activity*: the execution of a task or action by an individual. Thus, activity limitations are difficulties an individual may have in executing activities.
- *Participation*: involvement in a life situation and thus participation restrictions are problems an individual may experience in such involvement.
- *Environmental factors*: these make up the physical, social, and attitudinal environment in which people live and conduct their lives.
- *Contextual factors*: includes the features, aspects, and attributes of objects, structures, (participation) human-made organizations, service provision, and agencies in the physical, social, and attitudinal environment in which the people live and conduct their lives. Contextual factors include both environmental factors and personal factors.

Further details at www.who.int/classifications/icf

The full ICF is a complicated document. Basically, the scope of the ICF is to provide a description of situations with regard to human functioning. The ICF recognizes the importance not only of describing the functioning of an individual but also placing such functioning in to the social context. Fig 1.1 is taken from the WHO website and provides a useful summary.

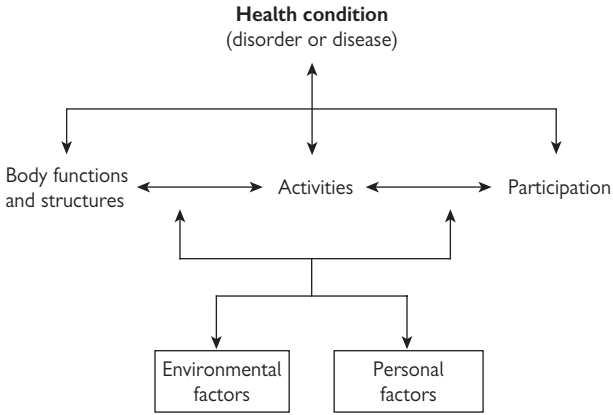


Fig 1.1 Interactions between the components of ICF. Reproduced from International Classification of Functioning, Disability and Health (ICF) [©] www.who.int/classifications/icf WHO press[®], with permission.



Medical model of disability

The new classification of impairment, activity, and participation is a step towards a social model of disability and a step away from the medical model of disability. These terms are in common usage in the field of rehabilitation and need further description. The medical specialty of rehabilitation medicine has come from an 'illness' background. It has in the past been a specialism that in general has been carried out by physicians with the support of nurses and therapists and delivered to disabled people. This health-related and illness-related perspective of disability is known as the medical model of disability. It assumes several things about the nature of disability (Box 1.4).

The philosophy of medicine has traditionally been to treat and to cure but in rehabilitation these outcomes are unlikely and the aim has been to normalize. This philosophy was reinforced by the initial classification of the WHO that produced a distinction between impairment, disability, and handicap. The medical model of disability usually implies that it is the physician who should take a leading role in the entire rehabilitation process—being team leader, organizing programmes of care, and generally directing the delivery of services for the disabled person. The doctor/patient relationship was the senior relationship in the medical model. Rehabilitation was born around the First World War when there was a very strong philosophy of the doctor telling injured servicemen how to behave, how to get better, and how to get back as quickly as possible to active duty. Such a model may have been appropriate in that cultural context but is now outdated. In recent years the central role of the physician has, in general, been subsumed by the central role of the multidisciplinary team. It is now realized that all health and social service professionals have their own role to play in the overall rehabilitation programme for the disabled person. However, even modern multidisciplinary rehabilitation is still largely based on the philosophy of the medical model—just a little watered down.

Box 1.4 Assumptions of the medical model of disability

- Disability is individualized. It is regarded as a disease state that is located within an individual. Thus, the problem and solution may both be found within that person.
- Disability is a disease state. A deviation from the norm. It inherently necessitates some form of treatment or cure.
- Being disabled, a person is regarded inherently as biologically or psychologically inferior to that of the able-bodied and normal human being.
- Disability is viewed as a personal tragedy. It assumes the presence of a victim. The objective normality state that is assumed by professionals gives them a dominant decision-making role often noted in a typical doctor/patient relationship.

After Laing R (1998). A critique of the disability movement. *Asia Pacific Disability and Rehabilitation Journal* 9, 4–8.

Social model of disability

Disability lobby groups have long suggested that the fundamental construct of disability is that a person's impairment is not the cause of their restriction of activity but rather it is the organization of society that discriminates against them. The social model focuses on the fact that disability is a construction of society and if society could accept and accommodate disabled people, both physically and attitudinally, then disability as a concept would be made redundant. The key features of the social model are listed in Box 1.5.

As the disability movement developed, particularly in the United States after the Vietnam War and in the UK in the 1980s, there was a feeling of antagonism between health professionals involved in disability on the one hand and activists in the disability movement on the other hand. There was limited cooperation. These two extreme positions have now rather softened and disabled people realize that health professionals have a clear and important role in helping to minimize activity restrictions. This is particularly true in the post-acute setting after, for example, stroke or traumatic brain injury. Even in longer-term disability, such as cerebral palsy or multiple sclerosis (MS), the health professional still has a key role to play. The crude dichotomy between the medical model and the social model is slowly but surely being replaced by a more appropriate halfway house—which could be called the *partnership model of disability*.

Box 1.5 Assumptions of the social model of disability

- A person's impairment is not the cause of restriction of activity.
- The cause of restriction is the organization of society.
- Society discriminates against disabled people.
- Attitudinal, sensory, architectural, and economic barriers are of equal, if not greater, importance than health barriers.
- Less emphasis is placed on the involvement of health professionals in the life of the disabled person.

Terminology

In the disability literature and in clinical practice it is vital to use correct terminology. This is not mere political correctness. Incorrect terminology can not only be demeaning but can indicate an inappropriate philosophy or attitude from the individual concerned or indeed from the whole multi-disciplinary team.

It is important to avoid terminology that implies dependency or terminology which just categorizes all disabled people. The word 'patient', for example, may be entirely appropriate for someone who is acutely ill and in the short term dependent upon medical and health professionals. However, in rehabilitation, if one agrees with the philosophy underlying the social model of disability, then disabled people are not ill and thus 'patient' is not a term that is appropriate. When the rehabilitation process is striving to give that person independence and develop new skills then terminology that implies the opposite should be avoided. There are a number of other group classifications that must be avoided including:

- Epileptics
- Stroke sufferers
- MS sufferers
- Spastics
- Young chronic sick
- The handicapped
- The disabled.

Although there is no universally accepted terminology it does seem reasonable to use the term 'disabled person' or 'person with a disability'. Correct terminology simply means that the person is being treated as an individual and not simply labelled as an example of a particular group.

As with many sections of society, it does seem acceptable for the group members themselves to use self-derogatory terms. People with spinal cord injuries will often refer to themselves as 'paras' or 'tetras' or even 'crips'.

Disability terminology is a minefield waiting to trap the unwary. The strength of feeling on these issues should not be underestimated.



Approaches to rehabilitation

Rehabilitation can be defined as an active and dynamic process by which a disabled person is helped to acquire knowledge and skills in order to maximize physical, psychological, and social function. It is a process that maximizes functional ability and minimizes disability and handicap—thus promoting activity and participation. There are three basic approaches in rehabilitation:

- Approaches to reduce the limitations on activity.
- Approaches designed to acquire new skills and strategies, which will reduce the impact of the limitations to activity.
- Approaches that help to alter the environment, both the physical environment and the social environment, so that a given activity limitation carries with it as little problem in participation as possible.

These are three vital concepts to the understanding of the rehabilitation process. The following is an example of these three approaches in action.

Case example

A middle-aged man has MS. He has been working quite successfully in the post room of a large factory. He is married with two children and has an active social life. However, in recent months he has developed increasing problems with walking secondary to developing paraparesis complicated by spasticity. In addition he has recently developed difficulties with urinary frequency and urgency. Rehabilitation, using our three basic approaches, could be structured as follows:

- Attempts could be made to reduce his activity limitation by appropriate treatment of his spasticity and use of medication to control his bladder symptoms.
- He could learn new skills. He could learn, for example, to walk with external support such as a stick or even use a wheelchair for longer distances such as from the office car park to his place of work. He could be taught intermittent self-catheterization to assist his urinary problems.
- Approaches could be made to alter his work environment. He may, for example, be advised on the use of a perching stool so he can support himself whilst sorting the post. He may need to approach his employer to change or reduce his hours if prolonged periods of standing are leading to increasing fatigue. At home there may be a need to provide grab rails in the toilet or other adaptations to the bathroom or kitchen. His wife and family will clearly need to be involved in order to understand his condition and adjust the family lifestyle to cope with his new problems. His wife may begin to share the driving if problems of spasticity are beginning to interfere with his driving abilities over long distances.

Thus, there are many simple pointers that could help him to minimize the impact of his condition on his work, on his family, and on his leisure time. The rehabilitation team needs to keep in mind these three basic approaches when planning the rehabilitation programme.



Goal setting

The essence of rehabilitation is goal setting. The first goal to be established is the final strategic aim. This can vary significantly. For some a long-term goal would be returning to a completely normal lifestyle. For others it may simply be to return home and remain at home with the help of carers. In other cases it may be to take up part-time employment or resume a particular leisure interest. Sometimes much discussion, and even argument, is necessary in order that all parties can agree a realistic long-distance strategic goal. After such a goal has been established then steps need to be identified in order to achieve that goal. If, for example, a long-term goal is to be independently mobile without the use of aids then achieving that goal can be broken down into a number of shorter-term subgoals. This may, for example, start with sitting without support, then standing without support, then walking with assistance, then walking with aids, and finally independent walking over increasing distances. It is important to emphasize that the goals must be precise. It is inappropriate, for example, to set a goal such as to walk with an improved gait. This is not specific or measurable and is obviously open to considerable subjective interpretation. A better subgoal would be to walk 20 metres with the aid of a stick within a period of 30 seconds. Thus, goals need to be both specific and measurable. They also need to be achievable within the context of the underlying natural history or pathophysiology of the condition. In order for progress to be seen it is also useful for goals to be time limited. In a post-acute rehabilitation setting it is useful to plan for achievable subgoals in a period of 1 or perhaps 2 weeks whereas in people with longer-term disabilities such goals could be set over a much longer timescale. Finally each goal must be relevant for that individual. It may be relevant for some people to learn how to make a cup of tea but for others it may be more relevant to learn how to open a can of lager!

In summary, it is useful to remember the mnemonic SMART when goals are being met. All goals should be:

- Specific
- Measurable
- Achievable
- Relevant
- Time limited.



Outcome measurement

The disabled person and the rehabilitation team need to know when the goals have been achieved. It is important for each goal to have a valid and reliable outcome measure attached to it. A number of specific outcome measures are discussed later in this handbook. In summary, there are a number of measures that have been designed to monitor overall disability and/or quality of life that are useful for assessing progress towards longer-term goals. Shorter-term subgoals often need more specific outcome measures. Such examples would be specific measures of mobility, such as timed walking speed, specific measures of hand function, such as the Action Research Arm Test, or more specific psychological parameters, such as an objective measure of memory. Any outcome measure used needs to be specific to the outcome it is measuring as well as being both valid and reliable. There is little point in using an outcome measure that has not been validated and shown to be reliable for the particular circumstances in which it is used. This would be like measuring cooking ingredients on scales with the wrong weights. However, the scales need not, and indeed preferably should not, be complicated or time-consuming. Whilst specific and somewhat complicated measures of mobility are sometimes useful, particularly in a research setting, simple day-to-day, but objectively measurable, goals can also be used in a busy clinical situation. The ability to hold a saucepan with a given volume of water for a particular period of time is an example of a simple and objective goal that may be of practical relevance to that individual.

Whilst objectively measurable goals are useful it should obviously not be forgotten that the opinion of the disabled person and/or their family is of primary importance and should always be able to colour and adjust any objective measure. Objective measurement, whilst vital, should not be allowed to override the opinions, perceptions, and wishes of the disabled person. Indeed the disabled person should be the central figure in the setting of goals and their appropriate measurement and monitoring.



Benefits of rehabilitation

The specific benefits of rehabilitation will become self-evident in the later sections of this book. However, in general terms the benefits of rehabilitation can be summarized as follows:

Functional benefit

There is now significant evidence that a coordinated interdisciplinary rehabilitation approach can produce better functional outcome than traditional unidisciplinary service delivery. In terms of stroke, for example, a rehabilitation unit will produce more functional gain, more quickly, with a better chance of returning home and with decreased morbidity and mortality. There is a similar case in the context of traumatic brain injury. There is even now evidence of a functional benefit of rehabilitation in deteriorating conditions, such as MS. These specific issues are discussed in later sections. There is also now evidence that short-term gains in a rehabilitation unit can generalize into longer-term functional improvements. If longer contact with the rehabilitation team is not established then the short-term functional gains and new skills may fade with time. This emphasizes the importance of not only post-acute rehabilitation units but also longer-term community support as well as rehabilitation support for those with deteriorating problems. What is not known is which elements of the rehabilitation process produce such functional benefits. Is it the basic rehabilitation process or is it simply the multidisciplinary or interdisciplinary team—or both combined? There is room for much more research on this subject but it is very likely that it is the whole rehabilitation process outlined in preceding sections that is key to such functional benefit.

Reduction of unnecessary complications

The disabled person can easily run into unnecessary and additional problems as a result of unrecognized or untreated complications. Untreated spasticity, for example, can lead to muscle contracture which further worsens functionality, increases dependency, and places the person at a risk of even more complications, such as pressure sores. Other significant problems can arise, for example, with inappropriately treated incontinence or unrecognized depression. The following sections in the book will outline many such examples.

Better coordination and use of resources

The person with complex and severe disabilities needs a variety of health, social, and other services. There is the clear potential for unnecessary overlap of assessment, treatment, and follow-up. The rehabilitation team should act as a single point of contact and a single point of information for the disabled person and their family. The team should be in the best position to coordinate the various services. Many people with complex disabilities now have the benefit of a case manager whose key role is to coordinate the different health and social inputs. Ideally the disabled person or a key family member should act in this role but this is not always possible, particularly for those people with residual cognitive or intellectual challenges.

Cost-effective use of resources

Unfortunately there are few studies that confirm the cost benefits of rehabilitation. There are some studies which, in general, have shown such benefits. In Newcastle upon Tyne in the UK, for example, a multidisciplinary MS team was established in the city. The economic benefits, in terms of reduced hospital bed usage and reduced outpatient visits, were offset by the cost of the team itself so that the whole team was introduced as a cost-neutral venture. It seems self-evident, although research is still needed, that better functional gains and avoidance of unnecessary complications should make the best use of scarce health and social resources. If a disabled person can be assisted back to work, even on a part-time basis, then it is a major cost saving for the national economy. About 80% of the costs of disability are due to lost employment opportunities.

Education, training, and research

There is a need for further studies in the whole realm of rehabilitation. Much more education, training, and research is needed. A rehabilitation team can act in such an education and research capacity and can help to enhance knowledge, reduce ignorance, and go some way to reducing the discrimination in disability.

Summary




This introductory chapter has outlined the concepts, principles, and processes of rehabilitation and illustrated some of the benefits. It is a process of education and enablement that centrally involves the disabled person and their family. It is a process that must be conducted through a series of specific goals on route to a long-term strategic aim. We now know that rehabilitation can produce real benefit in terms of functional improvement, fewer unnecessary complications, better coordination of services, and cost-effectiveness as well as providing a key role in general education, training, and research for both professionals and disabled people.

In summary the basic tasks of rehabilitation are:

- To work in partnership with the disabled person and their family.
- To give accurate information and advice about the nature of the disability, natural history, prognosis, etc.
- To listen to the needs and perceptions of the disabled person and their family.
- To assist in the establishment of realistic rehabilitation goals appropriate to that person's disability, family, social, and employment needs.
- To establish appropriate measures so that the disabled person and the rehabilitation team know when such goals have been obtained.
- To work with all colleagues in an interdisciplinary fashion.
- To liaise as needed with carers and advocates of the disabled person.
- To foster appropriate education and training of health and social service professionals as well as helping to meet the educational requirements of the disabled person.
- To foster research, both quantitative and qualitative, into the many aspects of the rehabilitation service—from scientific principles to the basic service delivery.

Rehabilitation has in the past been viewed as a rather vague and woolly process—often with justification. However, modern rehabilitation should be a combination of a precise science and the art of traditional medicine.

Further reading

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