

Chapter 1

Introduction

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1.1 What is rehabilitation?

As academics we are in the habit of defining any important terms that we use in our teaching or research publications and this is a practice that we expect from our students in their assignments. So it is hard to avoid starting a textbook on rehabilitation without defining precisely what we mean by this word. But at the same time a part of us already knows that we are doomed to fail in this rather ambitious task. Why this sense of pessimism?

It may be that it stems from our having sat through too many lengthy and heated discussions at learned conferences about how best to define rehabilitation. It is actually hard to find the right words to capture all the meanings that rehabilitation has for different people. It is especially hard to do this in a few pithy sentences since we all have different perspectives on rehabilitation depending on whether we are a health professional, a client or patient, a caregiver or relative of a patient, or a health manager with budgetary responsibility.

Or it might come from the knowledge that the field subsumes such a wide range of diseases and health conditions across the lifespan and such a growing range of methods for assessing and intervening in these conditions. So the physiotherapist who works with a 7-year-old boy with cerebral palsy to improve his gait is engaging in rehabilitation. Similarly the nurse who specializes in continence management in adults with multiple sclerosis is engaged in rehabilitation. But what about the physiotherapist

who works with an elderly man in the end stage of heart failure to maximize his strength, mobility and quality of life? Is this rehabilitation or palliative care?

Notwithstanding these concerns we shall begin this text on rehabilitation with a fairly searching consideration – what exactly is rehabilitation. To do this we will first clarify what rehabilitation is not – or at least what we the authors do not include as rehabilitation for the purposes of this book. Then we will consider a number of definitions that other authors have offered and attempt to tease out some of the key ideas that they share and also the problematic issues in arriving at a consensus definition of rehabilitation. Next, we will introduce the five core concepts that lie at the heart of this book. These core concepts will, to a large extent, define what we understand by the term rehabilitation. However, we will not conclude this chapter by selecting or proposing a single, ‘best’ definition of rehabilitation. Rather, we prefer to let all these definitions and concepts, ideas and opinions, percolate for a time while we examine our core themes in depth. Having completed that journey we will then ask you, in Chapter 7, to revisit the issue of how we might best define rehabilitation.

1.2 Setting boundaries – or what we don’t mean by rehabilitation

The word ‘rehabilitation’ has become a buzzword in the early 21st century. Wherever you look there is somebody using the word rehabilitation. But depending on who is talking or writing, who is being rehabilitated and the context in which they are using it, the meaning can vary considerably. Hardly a day goes by without us reading in the tabloid press about the latest film star or pop singer to go into ‘rehab’. Our daily papers also feature heated arguments in the Letters to the Editor section about the merits of spending taxes on trying to ‘rehabilitate’ hardened criminals – or whether we should simply be locking them away for longer sentences. Not so long ago dissident politicians in some communist countries occasionally disappeared from public life only to reappear some years later having been politically ‘rehabilitated’. A famous example of this was Deng Xiaoping who fell from grace during the Cultural Revolution but was later ‘rehabilitated’ and eventually became the leader of the People’s Republic of China. In searching electronic databases for our own research, using rehabilitation as keyword, we discovered that the term is also commonly used for the process of restoring land that has been ravaged by mining.

Interestingly, although none of these uses of the word have any great relevance for our text, they do all convey the sense of someone or something that has in some way become damaged or corrupted and then, through some prolonged process, has been restored to an acceptable or desirable state of existence.

However, we wish to be quite clear in this book, that in using the term rehabilitation, we are not referring to interventions for substance misuse problems, criminal offending, (perceived) political misdemeanours or natural environments devastated by human technology. In general we will use the term only for referring to ways of working with people who have some type of disability resulting from a congenital,

traumatic or chronic health condition. Some examples of these conditions are amputations, cerebral palsy, chronic obstructive pulmonary disease, lower back pain, multiple sclerosis, myocardial infarction, Parkinson's disease, spinal cord injury, stroke, schizophrenia and traumatic brain injury. However, this is starting to sound like a definition of rehabilitation, so it might be a good point to consider some of the ways in which other people have already defined the concept.

1.3 Some definitions of rehabilitation

Chambers Twentieth Century Dictionary gives the following definition of rehabilitate 'to reinstate, restore to former privileges, rights, rank etc.; to clear the charter of: to bring back into good condition, working order, prosperity: to make fit, after disablement or illness, for earning a living or playing a part in the world' (Macdonald, 1974, p. 1138).

The word rehabilitation comes from the Latin root 'habil' meaning to enable. Rehabilitation therefore means to 're-enable' or 'restore' and it is this sense of the word that is captured above in the diverse meanings attributed to it. However, our concern is primarily with the use of the word within healthcare and related settings. Rehabilitation is a relatively new term and specialty within healthcare (Gritzer and Arluke, 1985). One of the earlier definitions of rehabilitation within the healthcare realm is Jefferson's (1941) statement that rehabilitation should be: '...the planned attempt under skilled direction by the use of all available measures to restore or improve the health, usefulness and happiness of those who have suffered injury or are recovering from disease. Its further object is to return them to the service of the community in the shortest time' (Jefferson, 1941).

Notwithstanding its age, this statement of Jefferson's captures a number of key ideas that are integral to the aims and purposes of contemporary rehabilitation practitioners. There is the implication that rehabilitation is a complex process demanding a high level of professional skill and a holistic view of the individual. It is also clear from this definition that rehabilitation is not just about restoring or improving the person's physical health – their happiness is also vitally important. Even more contemporary is the assertion that rehabilitation enables the individual, not merely to feed and clothe themselves, but to participate as a citizen who makes an important contribution to their community.

Some 40 years after Jefferson, the World Health Organization (WHO), advanced the following definition: 'Rehabilitation is a problem-solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of disease, always within the limitations imposed by available resources and the underlying disease' (cited in Wade, 1992, p. 11).

This definition highlights a shift in thinking about rehabilitation as largely a medical concern, to a broader concern with the person's biological, psychological and social functioning i.e. the biopsychosocial model. Thus, rehabilitation is not simply a medical concern but requires the person to learn new skills and ways of coping

with their changed circumstances. The following definition from Barnes and Ward (2000, p. 4) is very similar in emphasizing rehabilitation as an educational or learning process that has physical, psychological and social dimensions: ‘Rehabilitation can thus 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’.

The final definition that we wish to consider here comes from Sinclair and Dickinson (1998, p. 1): ‘a process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients, service users and their family carers’. This concise statement emphasizes two key elements of modern rehabilitation practice that will also be emphasized in this book. First, is the notion that the most important goals in the rehabilitation process are those that matter most to the client or patient and only they can identify these goals. The second is the awareness that the patient’s family, relatives, caregivers, friends etc. are important participants in a good rehabilitation programme.

1.4 Some other issues in defining rehabilitation

Before introducing the five core themes of this book there are a couple of additional issues in defining rehabilitation that we need to consider. The first is the difference between *therapy* and *rehabilitation*. The second concerns a particularly strong challenge to traditional notions of rehabilitation and disability that arose in the 1970s.

Therapy versus rehabilitation

A major part of any programme of rehabilitation consists of the different kinds of therapies involved. These typically include occupational therapy, physiotherapy, and speech and language therapy (DeJong et al., 2005). These ‘core therapies’ may be supplemented with interventions offered by podiatrists, psychologists, social workers, family therapists, sport and exercise therapists, and experts in the use of assistive technologies. However, ‘doing’ therapy is not the same thing as ‘doing’ rehabilitation and rehabilitation is not just a synonym for therapies. Even worse is the assumption that after a spell in the neurosurgical, geriatric or orthopaedic ward, a patient enters ‘rehabilitation’ prior to discharge into the community.

The point at issue here is simply that rehabilitation means more than just physical therapy or spending two weeks in a ward with that name. It is actually about a comprehensive approach to working with the person and their family. This kind of approach can occur in an acute setting, a designated rehabilitation ward and also in the community until long after discharge from hospital. Moreover, some therapists practice therapy without a rehabilitation approach whereas some non-therapists (e.g. family, friends, community nurses, general practitioners) play an active role in the

rehabilitation process. In other words, although the various therapies are essential to rehabilitation, they are still only components of a broader and more complex process.

Disabling societies

Perhaps the strongest challenge yet to traditional medical understanding of how to best define rehabilitation has come from disability rights activists and academics in the field of disability studies (Braddock and Parish, 2001; Fougeyrollas and Beauregard, 2001). After the growth and influence of the civil rights movement in the USA in the 1960s, the flourishing of the women's movement in many countries, and an increasing awareness of the rights of psychiatric patients, the 1970s were a period of rapid growth in political activism among disabled people. The 1970s also saw the emergence of the social model of disability (Braddock and Parish, 2001). There are different perspectives on what exactly the social model of disability is and its implications but the following quotation from David Pfeiffer captures its essence nicely: 'Disability is not a medical nor a health question. It is a policy or political issue. A disability comes not from the existence of an impairment, but from the reality of building codes, educational practices, stereotypes, prejudicial public officials (judges, administrators, direct care workers), ignorance, and oppression which results in some people facing discrimination while others benefit from those acts of discrimination' (Pfeiffer, 1999, p. 106).

In this passage Pfeiffer is arguing that disablement is not merely the natural consequence of some biological defect within the individual but rather a form of discrimination or oppression that society inflicts upon those people who are perceived or labelled as physically or mentally impaired. Hence disability (and presumably rehabilitation too) is a political issue rather than just a medical or health issue. So, from this perspective, disability is more a reflection of how much a society values differences among people and allocates its resources to ensure that all people have the opportunity to participate fully in society. For example, disability is partly a product of architecture and buildings that for centuries were designed without even considering their accessibility for disabled people. Or to take another example, disability is a result of a competitive job market that actively or subtly discriminates against people with disabilities.

The arguments for and against a social model of disability are well beyond the scope of the present text (readers wishing to learn more about the social model of disability and different perspectives on it would do well to consult recent issues of the journal *Disability and Society* published by Taylor and Francis). However, the social model of disability has had a substantial and lasting impact on contemporary perspectives on rehabilitation. Evidence of this impact can be seen in the World Health Organization's (WHO) system for the classification of the 'consequences of disease' and its evolution since 1980. One of the most noticeable changes in the evolution from the International Classification of Impairment, Disease and Handicap (ICIDH) through the ICIDH-2 to the current International Classification of Functioning (ICF) (WHO, 2001) is the greater emphasis that is given to the role of environmental factors

(social and physical) in contributing to the process of disablement. Concomitant with this shift has been a transition from a largely biomedical or disease model to a biopsychosocial approach. Interestingly, the introduction to the ICF describes both the medical and the social models of disability and functioning and notes that the 'ICF is based on an integration of these two opposing models' (WHO, 2001, p. 20). We propose that the ICF provides a framework for rehabilitation, and is therefore the first core theme for this book (see Chapter 2).

The impact of the social model of disability is also reflected in the present book – most notably in Chapter 6, which is about the person in context. However, this book is written by academic health professionals, who have all worked in a range of rehabilitation settings, and so it will also reflect many aspects of the traditional medical model. There are risks involved in asserting that disability is purely a social construction and not a medical issue. One of these risks is that we ignore the reality that many disabled people are high frequency users of the health system. Their lives bring them into all too regular contact with health professionals. Consequently, in this book we adopt a perspective akin to that advocated by the ICF in which the aim is to bridge these two opposing viewpoints and to integrate biological, psychological and social elements of rehabilitation.

1.5 The core themes

Having set the scene we now introduce the five core themes that make up the content of Chapters 2 to 6 of this book. As we have mentioned, the first theme concerns the ICF, how this can be used as a framework for rehabilitation and act as a model and classification system. This chapter has been written by William Taylor, a rheumatologist who has worked on the use of the ICF for people with psoriatic arthritis, and by Szilvia Geyh, a psychologist who has worked for the ICF Research Branch in co-operation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI – the German Institute of Medical Documentation and Information). William and Szilvia's chapter describes the ICF, its development and terminology, and how it can be used for assessment and intervention evaluation. They go on to discuss the limitations and controversies about the ICF and its future development. The next theme concerns interprofessional rehabilitation and this chapter (Chapter 3) has been written by two allied health professionals who have worked clinically in rehabilitation settings (occupational therapy and physiotherapy) but who have also been lecturers involved with delivering interprofessional education. Claire Ballinger and Sarah Dean discuss teamwork and the roles and make-up of successful rehabilitation teams including service users.

After this, Chapter 4 goes on to describe the processes by which these teams engage in doing rehabilitation. William Levack, a physiotherapist, takes the lead on this chapter, and in particular provides a detailed account of one of the key processes in rehabilitation: goal setting. By the end of Chapter 4 we hope to have made it clear that the rehabilitation processes theme also includes the process of evaluating practice.

Outcome evaluation is therefore the next core theme and this is covered in much more detail in Chapter 5 by Richard Siegert, an expert in the development and evaluation of rehabilitation outcome measures, and by Jo Adams, an occupational therapist with expertise in the development, application and research of outcome measures for people with hand impairments. Our final core theme, the person in context, is placed last in our list of themes, not because it is the least important but rather because it is the ultimate focus of all our themes. The earlier chapters all touch on how the patient, client or service user is the focus of rehabilitation and in Chapter 6 Julie Pryor, nurse and director of a Nursing Rehabilitation Research and Development Unit in Australia, leads the discussion on how to place the person in their context and the importance of this for successful and meaningful rehabilitation to take place.

1.6 A word about terminology

Throughout the book we have asked our authors to consider the terminology they are using and to provide definitions as appropriate. However, in many instances there are several terms that can be used interchangeably, for example patient, client, or person can all be used to prefix 'centred care'. Rather than attempt to be popular or to be prescriptive in our terminology, we will use whichever word provides the best fit for the sentence in question. For example, the term 'patient-centred care' is often used in this book because it clearly identifies the person in question, differentiating them from say, relatives or carers.

1.7 Summary

The final chapter of this book (Chapter 7) revisits the key messages of our five core themes; identifies the limitations in current thinking and practice and suggests some of the likely developments for the future of rehabilitation. We hope that you will enjoy this book; it is not profession or discipline specific but does cover a range of examples from differing conditions, rehabilitation approaches and types of research. Thus, we believe there is something here for everyone involved in interprofessional rehabilitation.

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