

Neuropsychological Rehabilitation:

A Modular Handbook

Neuropsychological Rehabilitation and People With Dementia



Linda Clare

Neuropsychological Rehabilitation and People with Dementia

Rehabilitation provides a core concept around which to organise support, intervention and care for people with impairments in memory and other cognitive functions. This book introduces a conceptual framework and rationale for the application of a neuropsychological rehabilitation approach for people with dementia, helping them to manage, bypass or overcome these problems and experience optimum well-being.

Methods and techniques of cognitive rehabilitation are described and the process of goal-setting is discussed in detail, showing how effective strategies may be linked to form an individualised, goal-oriented approach to intervention. The application of a rehabilitation approach in real-life contexts is explored, demonstrating the role and value of neuropsychological rehabilitation within a holistic, psychotherapeutic framework of care and support.

This overview of the neuropsychological rehabilitation approach to dementia care will be of great interest to psychologists as well as to those studying or practising in the area.

Neuropsychological Rehabilitation: A Modular Handbook

The *Neuropsychological Rehabilitation: A Modular Handbook* series covers a wide range of cognitive deficits and will prove an invaluable resource for the neuropsychologist and others working with neurologically impaired people. The series editors, Barbara A. Wilson and Ian H. Robertson, are also editors of the international journal *Neuropsychological Rehabilitation*.

Linda Clare is a chartered clinical psychologist and clinical neuropsychologist. She is currently Reader in Psychology in the School of Psychology, University of Wales Bangor. In 2003 she received the May Davidson Award from the British Psychological Society for her contribution to the development of clinical psychology.

Neuropsychological Rehabilitation and People with Dementia

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Contents

<i>Series preface</i>	vii
<i>Figures and tables</i>	ix
<i>Acknowledgements</i>	xi
1 Introducing neuropsychological rehabilitation and people with dementia	1
<i>Overview of the book</i>	2
<i>Conclusions</i>	4
2 Dementia, disability and rehabilitation	5
<i>Dementia: A brief overview</i>	5
<i>Conceptual frameworks for understanding dementia</i>	8
<i>Applying a biopsychosocial framework to AD</i>	10
<i>The relevance of rehabilitation</i>	19
<i>Conclusions</i>	22
3 Understanding the experience of dementia	23
<i>Understanding the experience of the person with dementia</i>	23
<i>Viewing the person with dementia in context</i>	31
<i>The experience of family caregivers</i>	32
<i>Social participation in early-stage dementia</i>	35
<i>Conclusions</i>	37
4 Awareness and the person with dementia	39
<i>Empirical evidence</i>	40
<i>Theoretical and conceptual issues</i>	41
<i>Methodological issues</i>	45
<i>Practical implications of variations in awareness</i>	47
<i>Conclusions</i>	50

5 Neuropsychology, plasticity and learning in dementia	53
<i>Experimental evidence of learning</i>	54
<i>Memory systems and processes</i>	55
<i>Brain pathology and neural plasticity</i>	59
<i>Possibilities for prevention</i>	62
<i>Conclusions</i>	63
6 Towards individualised rehabilitation interventions	65
<i>Reality orientation and cognitive stimulation</i>	66
<i>Cognitive training</i>	70
<i>Cognitive rehabilitation</i>	79
<i>Conclusions</i>	82
7 Assessment for cognitive rehabilitation	83
<i>Diagnostic assessment</i>	83
<i>Assessment for cognitive rehabilitation</i>	85
<i>Conclusions</i>	91
8 Methods of memory rehabilitation	93
<i>Facilitating remaining episodic memory functioning</i>	94
<i>Facilitating procedural memory functioning</i>	103
<i>External memory aids</i>	104
<i>Rehabilitation for people with fronto-temporal dementia</i>	109
<i>Conclusions</i>	110
9 Clinical application of cognitive rehabilitation	113
<i>Goal setting</i>	113
<i>Application of specific strategies</i>	115
<i>Developing a comprehensive intervention plan</i>	123
<i>Conclusions</i>	127
10 An holistic approach to neuropsychological rehabilitation in dementia	129
<i>Psychotherapeutic and systemic perspectives</i>	130
<i>Service contexts</i>	132
<i>Evaluating outcome</i>	134
<i>Current evidence</i>	135
<i>Future directions</i>	136
<i>Conclusions</i>	137
<i>References</i>	139
<i>Author index</i>	165
<i>Subject index</i>	173

Series preface

Rehabilitation is a process whereby people who have been impaired by injury or illness work together with health service staff and others to achieve their optimum level of physical, psychological, social and vocational well-being (McLellan, 1991). It includes all measures aimed at reducing the impact of handicapping and disabling conditions and at enabling disabled people to return to their most appropriate environment (WHO, 1986; Wilson, 1997). It also includes attempts to alter impairment in underlying cognitive and brain systems by the provision of systematic, planned experience to the damaged brain (Robertson & Murre, 1999). The above views apply also to neuropsychological rehabilitation, which is concerned with the assessment, treatment and natural recovery of people who have sustained an insult to the brain.

Neuropsychological rehabilitation is influenced by a number of fields both from within and from without psychology. Neuropsychology, behavioural psychology and cognitive psychology have each played important roles in the development of current rehabilitation practice. So too have findings from studies of neuroplasticity, linguistics, geriatric medicine, neurology and other fields. Our discipline, therefore, is not confined to one conceptual framework; rather, it has a broad theoretical base.

We hope that this broad base is reflected in the modular handbook. The first book was by Roger Barker and Stephen Dunnett, which set the scene by talking about "Neural repair, transplantation and rehabilitation". The second title, by Josef Zihl, addressed visual disorders after brain injury. The most recent book by Barbara Wilson, Camilla Herbert, and Agnes Shiel focused on behavioural approaches to rehabilitation. Future titles will include volumes on specific cognitive functions such as language, memory and motor skills, together with social and personality aspects of neuropsychological rehabilitation. Other titles will follow as this is the kind of handbook that can be added to over the years.

Although each volume will be based on a strong theoretical foundation relevant to the topic in question, the main thrust of a majority of the books will be the development of practical, clinical methods of rehabilitation arising out of this research enterprise.

The series is aimed at neuropsychologists, clinical psychologists and other rehabilitation specialists such as occupational therapists, speech and language pathologists, rehabilitation physicians and other disciplines involved in the rehabilitation of people with brain injury.

Neuropsychological rehabilitation is at an exciting stage in its development. On the one hand, we have a huge growth of interest in functional imaging techniques to tell us about the basic processes going on in the brain. On the other hand, the past few years have seen the introduction of a number of theoretically driven approaches to cognitive rehabilitation from the fields of language, memory, attention and perception. In addition to both the above, there is a growing recognition from health services that rehabilitation is an integral part of a health care system. Of course, alongside the recognition of the need for rehabilitation is the view that any system has to be evaluated. To those of us working with brain-injured people including those with dementia, there is a feeling that things are moving forward. This series, we hope, is one reflection of this move and the integration of theory and practice.

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Barbara A. Wilson
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Other titles available in the series:

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by Joseph Zihl

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by Barbara A. Wilson, Camilla M. Herbert, & Agnes Shiel

Figures and tables

Figure 2.1	Dialectical model of dementia	9
Figure 2.2	Disability model of dementia	10
Table 2.1	Areas to consider in formulating a comprehensive intervention approach for people with AD and their families	11
Figure 3.1	The subjective experience of developing memory problems in early-stage AD	25
Figure 3.2	Coping styles in early-stage AD	26
Figure 5.1	Dissociable systems in long-term memory	56
Figure 5.2	Dissociable systems in working memory	57
Figure 5.3	Memory processes	58
Figure 5.4	Brain activation during successful associative learning	61
Figure 9.1	Goal attainment ratings – Malcolm	116
Figure 9.2	Goal setting and implementation – Evelyn	117
Figure 9.3	Goal setting and implementation – Alan	118
Table 9.1	Description of the participants	120
Figure 9.4	Goal attainment ratings for personal rehabilitation goals following intervention	123

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1 **Introducing neuropsychological rehabilitation and people with dementia**

This chapter introduces the concept of neuropsychological rehabilitation for people with dementia and presents an overview of the book.

The way we think about dementia has undergone significant changes in recent years. There is a new emphasis on living with, and managing, the effects of dementia, in order to maintain and support well-being and quality of life. This emphasis reflects the aims of rehabilitation and has relevance right across the spectrum of dementia severity. Rehabilitation has the potential to contribute to quality of life for people with dementia and their families. Because neuropsychological change is central to dementia, a neuropsychological focus is important when considering rehabilitation for people with dementia. At the same time, dementia is about much more than neuropsychological change, and rehabilitation for people with dementia should take account of the whole person, with an understanding of subjective experience and needs. In this book, I consider what we know about the experience of dementia at a neuropsychological and also at a psychosocial level, and I attempt to integrate these elements to provide a comprehensive and holistic framework for neuropsychological rehabilitation in this context.

At present, we have no cure for the dementias, and although some pharmacological treatments offer modest benefits for a proportion of individuals with dementia, there are no effective medical interventions to reverse decline or prevent progression of impairments. In this context, rehabilitative approaches are especially important. Rehabilitative approaches, most commonly thought of in relation to non-progressive problems, for example following brain injury, can also be applied to the whole range of progressive neurological disorders. Much of the research in this area, including my own, has focused on people in the early stages of a primary progressive dementia, most commonly Alzheimer's disease (AD). The focus taken in this book will reflect this emphasis, referring mainly to work with people who have early-stage AD. Nevertheless, many of the principles discussed here might be applied to assist people experiencing other forms of dementia, and

2 *Neuropsychological rehabilitation in dementia*

indeed other progressive neurological disorders that may result in cognitive impairment.

In preparing this book I have attempted to do two things. First, I have aimed to review the research literature relevant to neuropsychological rehabilitation in dementia and to present a concise and helpful account of the foundations and rationale for the approach, the methods and techniques involved, the application of the approach and how it might develop in the future. Second, I have drawn on experience gained in my own research studies and clinical practice to describe aspects of the practical application of cognitive rehabilitation in early-stage AD, and I illustrate these with real-life examples. While the focus here is on ‘neuropsychological’ rehabilitation, I hope that this volume will be of value not just to psychologists, but also to other health professionals working in dementia care who are keen to offer a constructive, practical intervention approach.

Overview of the book

In attempting to introduce the concepts of neuropsychological rehabilitation for people with dementia, I begin with a discussion of how dementia is understood and the relevance of rehabilitation, and consider the psychosocial impact of dementia. I then go on to address the neuropsychological aspects and the way in which cognition-focused interventions have developed. These early chapters provide the background and rationale for applying neuropsychological rehabilitation with people who have dementia in clinical settings. This sets the scene for chapters focusing on the current application of neuropsychological rehabilitation, and addressing assessment, specific rehabilitation strategies, and clinical applications. Finally, I present an holistic model of neuropsychological rehabilitation for people with dementia. Here I briefly outline the content of each of the chapters.

Chapter 2 begins with an overview of dementia, considering how it is currently defined and categorised into various sub-types, how it relates to other conditions, and how frequently it occurs in different age-groups. This leads into a discussion of how dementia may best be understood. Recent developments in our thinking about dementia have made a powerful case for moving beyond a standard disease model to consider dementia within a biopsychosocial framework and place the person with dementia in context. The application of a biopsychosocial framework is discussed, showing how dementia may usefully be viewed in terms of disability, and how this points to the relevance of a rehabilitation approach. I suggest that rehabilitation interventions that aim to impact on the disability and handicap resulting from the underlying neurological impairments, and in particular to reduce excess disability, have the potential to benefit people with dementia and their families.

Adopting a biopsychosocial framework encourages us to address the psychosocial impact of dementia, and I discuss this with a particular

emphasis on people with early-stage AD. Chapters 3 and 4 consider current knowledge in this area and what it tells us about the potential for rehabilitation. Chapter 3 focuses on the subjective experience of AD. Models of the subjective experience of the person with early-stage AD, and how people with AD make sense of their condition, are reviewed. In order to place the person with dementia in context, the nature of interactions with family caregivers is discussed, aspects of the experience of family caregivers are outlined, and recent work focusing on social participation in dementia is introduced. Finally, implications for intervention are described, and the role of rehabilitation in this context considered. Following on from the account of subjective experience, Chapter 4 introduces the related issue of awareness. The extent to which the person with AD is aware of the developing difficulties and changes has important implications for the potential to engage in rehabilitation. This chapter reviews the theoretical frameworks that are available to help in making sense of changes in awareness, and the methods that are currently used to assess awareness. Practical implications of variations in awareness, and the relationship between awareness and outcome of rehabilitation interventions, are discussed.

Having explored the psychological and social experience of AD, in Chapter 5 I discuss the neuropsychological changes that dementia brings, again with particular reference to AD. Chapter 5 explores how theoretical models from neuropsychology combine with experimental evidence on learning, behaviour change and neural plasticity to provide a basis for cognitive rehabilitation interventions in early-stage Alzheimer's disease. I introduce a range of evidence suggesting that people with early-stage AD may benefit from such approaches, provided they are appropriately targeted and based on a sound understanding of the profile of cognitive change and its implications for everyday functioning.

Before considering how neuropsychological rehabilitation can best be put into practice in dementia care, it is useful to reflect on the history of psychological interventions in dementia, to consider how neuropsychological rehabilitation relates to other approaches, and to review some of the available methods and techniques. Chapter 6 provides a brief history and overview of cognition-focused interventions for people with dementia in order to help clarify the distinctive aspects of neuropsychological rehabilitation in this context and how it differs from other forms of cognition-focused intervention. This chapter sets the scene for a comprehensive discussion of the application of cognitive rehabilitation in the following chapters.

The starting point for effective cognitive rehabilitation interventions is a comprehensive assessment. Chapter 7 provides a brief overview of the diagnostic assessment of dementia, followed by a longer discussion of assessment for cognitive rehabilitation, outlining the areas to be considered in an assessment and the way in which information from the assessment contributes to planning and conducting the intervention. In Chapter 8 I

4 *Neuropsychological rehabilitation in dementia*

review a range of methods that can be used as the building-blocks of memory rehabilitation interventions. Methods that have been used to assist people with early-stage dementia in learning or relearning information include principles such as effortful processing and errorless learning, along with specific techniques such as spaced retrieval and mnemonic methods. The relevance and effectiveness of these methods are considered. Methods for maintenance or development of practical skills of everyday living are discussed along with methods of familiarising people with dementia with new memory aids and teaching the use of memory aids. In Chapter 9 I explore how the various specific methods and techniques described in earlier chapters can be linked to form a comprehensive, individualised clinical intervention for the person with early-stage AD. The concept of personal goal setting provides a central focus for applying the available techniques creatively in a way that has the potential to enhance the person's functioning in everyday life.

Drawing together the many themes discussed throughout the book, Chapter 10 describes an holistic approach to neuropsychological rehabilitation for people with dementia. Interventions are considered in relation to psychotherapeutic and systemic perspectives. Service and policy contexts are briefly discussed, and methods for evaluating treatment outcome are considered. The chapter concludes by outlining current evidence for the efficacy of cognitive rehabilitation and suggesting some future directions for the further development of this approach.

Conclusions

In this book I hope to stimulate a greater understanding of what it is like to experience dementia, to convey the importance and relevance of applying the concept of rehabilitation to assist people with dementia and progressive neurological disorders, and to encourage readers to incorporate the principles of rehabilitation into their work with people who have dementia. As later chapters show, there are many possible ways of doing this, and therefore I hope that all readers will be able to gain some useful ideas that they can apply in their own work settings.

2 Dementia, disability and rehabilitation

A brief overview of dementia leads into a discussion of how this condition may best be understood. The application of a biopsychosocial model to AD is discussed, showing how dementia may usefully be viewed in terms of disability. This points to the relevance of a rehabilitation approach. Rehabilitation interventions that aim to impact on the disability and handicap resulting from the underlying neurological impairments, and in particular to reduce excess disability, offer tremendous scope to benefit people with dementia.

In this chapter, I begin by reflecting on current understandings of dementia and the relevance of rehabilitation. As I said in the introduction, the way in which we view and understand dementia has undergone considerable change in recent years, and dementia care focuses increasingly on finding ways of managing disability so as to support or maintain well-being. Through exploration of the biological, psychological and social aspects of dementia I will highlight the relevance and scope of neuropsychological rehabilitation.

Dementia: A brief overview

Dementia is a broad term encompassing a number of different progressive neurological conditions. A general definition describes dementia as ‘a clinical syndrome characterised by loss of function in multiple cognitive abilities in an individual with previously normal (or at least higher) intellectual abilities and occurring in clear consciousness’ in the absence of any other disease process that could account for the observed cognitive decline (Whitehouse, Lerner, & Hedera, 1993, p. 603). Prevalence estimates vary, but dementia is thought to affect about 2.5 per cent of all people over 65, and prevalence doubles with every 5 years of increasing age, so that about 10 per cent of all people over 75, and 40 per cent of all people over 85, are affected (R. S. Turner, 2003). Thus dementia is associated with increased age, and incidence is most common between the ages of 70 and 90; there is

some suggestion that incidence rates may be reduced in those who survive beyond the age of 90 (McKeith & Fairbairn, 2001). Increases in life expectancy lead to an associated increase in the number of people who are at risk of developing dementia. However, dementia does occur in younger people, and dementia with onset before the age of 65 is also a matter of concern (Cox & Keady, 1999). Dementia accounts for a considerable proportion of health care expenditure in developed countries. As rates of population growth for older people increase in developing countries, so concern about dementia is likely to rise in these societies as well (Pollitt, 1996). Recent years have also seen a growing awareness of the prevalence of dementia among people with intellectual disability as they age (C. Oliver, Adams, & Kalsy, in press).

Dementia needs to be distinguished from other psychiatric and medical disorders that may produce apparently similar effects, such as depression, as well as from the ill-effects of nutritional deficiencies, exposure to toxins or iatrogenic consequences of taking prescribed medications (Christensen, Griffiths, MacKinnon, & Jacomb, 1997). Some of these conditions are treatable, although depression in particular may still represent a risk factor for later development of dementia (J. O'Brien, Ames, Chiu, Schweitzer, Desmond, & Tress, 1998). All of these possibilities must be excluded before arriving at a diagnosis of dementia.

There are numerous possible types of dementia (McKeith & Fairbairn, 2001). The most frequent dementia diagnosis is Alzheimer's disease (AD), accounting for approximately 50–60 per cent of all dementia diagnoses. Vascular dementia on its own accounts for about 10 per cent of all dementia diagnoses, but is often present alongside other forms of dementia. Dementia with Lewy bodies accounts for about 15–20 per cent of diagnoses and may often co-exist with Alzheimer's disease. Less common sub-types of degenerative dementia include fronto-temporal dementia, encompassing the subcategories of frontal dementia and semantic dementia, which accounts for 10–20 per cent of dementias with age of onset between 45 and 70 years, and Huntington's disease, with a prevalence of 4–7 cases per 100,000 people. Dementia may also arise in Parkinson's disease, affecting 10–80 per cent of those diagnosed, in multiple sclerosis, affecting 50–66 per cent of those diagnosed, and in other very rare progressive neurological disorders, such as progressive supranuclear palsy (PSP), Creutzfeld-Jakob disease, limbic encephalitis, progressive multifocal leucoencephalopathy and sub-acute sclerosing panencephalitis. Dementia may also result from trauma, for example following head injury or anoxia, from toxic exposure, as in alcohol-related dementia, from infection, as in AIDS dementia complex, or from space-occupying lesions, metabolic problems or other causes such as normal pressure hydrocephalus. A distinction is commonly made between cortical and subcortical dementias. Cortical dementias, of which AD is one, primarily affect cortical areas of the brain. In subcortical dementias, such as PSP or Huntington's disease, the normal regulatory effect that subcortical

structures exert on the cortex is diminished or lost. All these various forms of dementia have different neuropsychological profiles, particularly in the earlier stages, and consequently different implications for intervention (Brandt & Rich, 1995). Since the application of neuropsychological rehabilitation approaches to date has focused on the most commonly diagnosed forms of dementia, and especially Alzheimer's disease, this focus is also reflected in the chapters that follow, although where appropriate, mention is made of potential relevance to other groups. Many of the principles discussed have some relevance to people with other forms of dementia.

Although several different sub-types of dementia have been identified, it is important to note that diagnosis and classification are not always straightforward. A diagnosis of AD can only be confirmed fully where post mortem examination makes it possible to clarify the precise nature of the brain pathology (R. S. Turner, 2003). Some forms of dementia may co-exist, and in such cases it is hard to be sure about the relative contribution of each to the observed difficulties. For example, some individuals may have a mixed type of dementia with features of both AD and vascular dementia (Norris, MacNeill, & Haines, 2003). AD itself may represent a heterogeneous category, encompassing multiple aetiologies and presenting with different profiles of neuropsychological change and progression (R. G. Morris & Becker, 2004).

The main sets of diagnostic criteria for AD and vascular dementia (American Psychiatric Association, 1995) require impairment in at least two domains of cognition, of a degree that affects everyday functioning. Thus, at the point of diagnosis, the level of impairment is already significant. Recently, interest has focused on detecting those with very early signs of dementia and those most at risk of developing dementia. Again, this is not always straightforward. Most, though not all, older people experience some decline in cognitive functioning with age, and there is wide variation in what might be considered 'normal' performance (Kester, Benjamin, Castel, & Craik, 2002). Some individuals fall into the area between 'normal' cognition and dementia, with difficulties that are more extensive than the norm but do not impact significantly on functioning and are not of such an extent as to meet criteria for a dementia diagnosis. Various terms and definitions have been applied to this group, such as 'benign/malignant senescent forgetfulness' (Kral, 1962), 'age-associated memory impairment' (Crook, Bartus, Ferris, Whitehouse, Cohen, & Gershon, 1986) or 'age-associated cognitive decline' (American Psychiatric Association, 1995); currently, they are most likely to be described as experiencing 'mild cognitive impairment' (MCI; Petersen, 2004). Individuals with MCI are at increased risk of going on to develop dementia, and some researchers have argued that MCI represents a very early stage of AD (J. C. Morris et al., 2001). The approaches to intervention for people with dementia described in this book are likely to have considerable relevance to people who meet criteria for MCI (Woods & Clare, 2006).