

Rehabilitation therapy in MS; a short-term, expensive, placebo

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Rebuttal

As clinicians working in the field of multiple sclerosis (MS), we find that it is evident from the moment an individual receives a diagnosis of MS, that they are transformed into a ‘person living with MS.’¹ While most of us will see a small percentage of individuals who remain relatively symptom-free, these form the minority of our caseload and make relatively few demands on our services. The majority of our patients experience a multiplicity of interrelated physical, cognitive and psychosocial problems; which typically progress over time, and which are shown to unequivocally impact in a negative way on the quality of their lives and the lives of their families.

Providing a diagnosis and conveying it in a sensitive manner is widely recognised as being a considerable challenge, but most would agree that effectively managing the person’s condition over the long term is even more challenging. Most of us have probably reflected on how we would cope with living with this disease for which there is currently no cure: What support would we need from health and social care services to adapt successfully to the changing demands the disease imposes on us?

Underlying many of these questions is the concept of rehabilitation, defined by the World Health Organisation² as ‘a problem solving educational process by which those who are disabled by injury or disease realise their optimal physical, mental and social potential and are integrated into their most appropriate physical and social environment.’ This acknowledges that rehabilitation is not a specific treatment of a single symptom, but rather a concept in which the full range of disabilities are treated in a coordinated way by multi-disciplinary team members.¹ Benefits for the individual are achieved by ensuring that the primary focus of management is on the behavioural aspects of the disease. The strong educational bias, which is integral to rehabilitation, aims to equip the person with effective coping skills, so they can manage deficits and apply solutions to challenges.

That the benefits of rehabilitation extend beyond disability is evidenced by the fact that patient-perceived benefit does not correlate strongly with improvements in disability, but appears to capture other elements. While the exact nature of these elements is not yet fully understood, it is

thought to reflect support with adjustment, problem-solving skills, and greater understanding of their available options. It is suggested that these benefits will persist even when disability continues to accrue.³ As such, rehabilitation is a concept (as distinct from a service) which should underpin all services dealing with people with MS throughout the course of their disease. An understanding of this philosophy is essential to comprehending why we believe that the benefits gained from rehabilitation are neither short term, nor disproportionately expensive, when compared to other medical interventions.

Over the past few decades there has been a gradual accumulation of scientific evidence to support the effectiveness of rehabilitation interventions in MS, both in terms of packages of care and single interventions. Cochrane systematic reviews provide strong evidence of the short-term effectiveness of multi-disciplinary packages of care in improving activities and participations;⁴ and also exercise therapy in improving muscle function, exercise tolerance and mobility.⁵ Moderately strong levels of evidence exist in relation to improvements in mood,⁵ while low levels of evidence exist for neuropsychological rehabilitation interventions.⁶ The evidence from these systematic reviews is complemented by randomised controlled clinical trials in other areas such as vestibular rehabilitation⁷ and cognitive behavioural therapy for fatigue.⁸ Of note, the benefits are achieved in the apparent absence of harmful side effects. Promising evidence is also beginning to emerge from clinical trials involving alternative models for delivering rehabilitative care (e.g. telerehabilitation).⁹

Currently, the mechanisms underpinning improvements remain unclear. It is not known whether changes occur by reversing the impact of secondary complications (such as deconditioning), the education of compensatory strategies (e.g. re-education of functional movement or the use of

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cognitive strategies) or whether the impairments themselves can become reversed; however, preliminary evidence from MRI and patient-reported studies is beginning to emerge, suggesting that rehabilitation approaches such as exercise may have a possible disease-modifying effect with the potential to slow down the disease process and impact immune function.¹⁰ Changes in fMRI activity have also been shown, following cognitive rehabilitation.¹¹ Whilst these claims should be viewed with caution until a greater body of evidence is available, it is recognised that this information has the potential to provide important insights into how rehabilitation interventions might best be implemented in the future.

Determining whether or not rehabilitation interventions are cost-effective is currently impossible, given the paucity of available data. This is perhaps unsurprising, given the enormous methodological challenges experienced in providing meaningful cost-effectiveness data in areas such as drug therapy, where the existing evidence base is more robust and the resources invested in research is overwhelmingly greater. It has been calculated that costs increase steeply with increasing disease severity.¹² Key times exist when rehabilitation interventions are useful and drug therapy options are limited: For example, the mean cost per patient with severe disease (EDSS ≥ 7.0) is 4–5 times higher than the cost for a patient with mild disease (EDSS score <3.5).¹² Of particular relevance to rehabilitation, studies show that the indirect costs associated with informal care and loss of earnings far exceed those associated with actual health care costs, accounting for 71.6% of the total service costs in a related UK-based study.¹³ Meaningful evaluations of cost effectiveness should therefore consider not only the direct health care costs, but also the indirect societal costs of MS; which include the need for formal and informal care, the impact on the individual's work capacity and on their care-giver's burden, as well as intangible costs such as suffering. The strong levels of evidence demonstrating improved levels of activities and participation,⁴ together with the array of evidence indicating that a coordinated management of symptoms such as spasticity, pain and urinary and bowel incontinence can improve the individual's ability to manage their home and work environments and improve their quality of life,¹⁴ will serve to underline our argument that rehabilitation is not "a medically-ineffectual treatment" (i.e. a placebo).

In summary, we recognise that there is an urgent need for well-conducted longer-term trials of rehabilitation interventions, using clinically-relevant outcome measures in patients with different types of MS, and at different levels of disability, to definitively establish the effectiveness of many rehabilitation interventions. This is important, so that we can improve our ability to make evidence-based decisions about the allocation of resources. Clearly, a key priority is to determine who benefits most from (and should receive) specific rehabilitation interventions. Currently, too few methodologically-rigorous studies have examined these

questions. A lack of evidence; however, does not equate to evidence against a procedure. To draw firm conclusions that are based on systematic reviews that synthesise evidence from small numbers of randomised controlled trials of sometimes poor methodological quality, is undoubtedly overly simplistic. Evidence-based practice acknowledges this by ensuring that clinical judgements are based on a broader perspective of evidence, valuing a range of research methodologies, and including the experiences of both clinicians and patients. This is clearly reflected by the recommendations made within National¹⁴ and International MS Guidances,¹ and the opinions of people affected by MS who regard rehabilitation as an essential component of quality healthcare. And for the skeptics who dismiss this evidence because of its flawed methodology, we simply ask them one question: 'If faced with the reality of coping with a myriad of symptoms which impact significantly on their quality of life, and with no available cure, what intervention would they choose: rehabilitation or an equivalent sugar pill?'

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Conflict of interest statement

The authors declare that there are no conflicts of interest.

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