

# Rehabilitation Research: We Should Care and We Should Act

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## INTRODUCTION

In 1925, Dr. William J. Mayo was credited as saying “Rehabilitation is to be a master word in medicine.” As a field, rehabilitation medicine has a very exciting opportunity to serve society through a focus on human health, function, and participation. Physiatrists are poised to play a major role in improving the quality of life of patients and the health of society in an age of increasing numbers of older adults, an increasing prevalence of obesity, and competing needs to preserve health while reducing costs. The field has expanded to incorporate technology, sports and performing arts medicine, and image-guided interventions while still incorporating neurologic and musculoskeletal rehabilitation for children, workers, and older adults. Although diverse, rehabilitation medicine aims to optimize musculoskeletal and neurological human function.

However, in physical medicine and rehabilitation (PM&R) today, there is a gap between clinical need and the evidence base. Although evidence is increasingly necessary to provide care and services and to receive reimbursement, research has not kept pace with rehabilitation practice and services. Given that PM&R is a relatively small field with a growing, but still very limited research infrastructure, collaboration to integrate expertise and share resources is important to maintain current essential services and to continue to advance the specialty.

The U.S. federal definition of research is “a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge” [1]. Rehabilitation research focuses on advancing knowledge regarding health and function, social participation and community living, and disabilities—employment. It is widely recognized that there is a shortage of high-level studies of rehabilitation [2].

According to the U.S. Census Bureau, the prevalence of self-reported disability among community-dwelling Americans in 2005 was 22%, affecting 47.5 million people [3]. The leading 2 causes of disability are arthritis and back pain [4]. Given that this survey excluded those living in institutions such as nursing homes and the expected doubling of the population older than the age of 65 in the next 20 years, disability is likely the most prevalent problem affecting the lives of Americans. Physical rehabilitation services are essential to the functional status and independence of people with disabilities, most of whom are disabled as the result of musculoskeletal disease. Despite this fact, there are few federally funded rehabilitation research projects in comparison with other fields, and there are very few evidence-based practice guidelines for rehabilitation therapies.

Recognizing this gap, in 2005 Congress appropriated nearly \$3.1 billion for rehabilitation services and disability research, of which \$109 million was directed to the National Institute on Disability and Rehabilitation Research (NIDRR), and mandated that an Interagency Committee on Disability Research “report on the existing, agency-wide research activities relating to physical rehabilitation, opportunities for future physical rehabilitation research, and recommendations on how physical rehabilitation research can be enhanced within the departments and agencies.” The 2007 Interagency Committee on Disability Research report found that few rehabilitation studies addressed questions of the specific type, dose, and duration of effect of therapies, or questions of how to improve existing therapies either through modification or combination with other therapies [3]. The report emphasized the importance of development of reliable measures of health and functional status for people with disabilities, the need for alternative study designs for questions not

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amenable to randomized controlled trials (RCTs), and the need to study the role of physical rehabilitation for disease prevention and first-line treatment to reduce the need for other more expensive therapies.

Regrettably, in 2006, 2007, and 2008 respectively, PM&R departments received only 10 of 4670, 14 of 5162, and 11 of 4919 NIH-funded research grants [5]. Furthermore, as a research area, "rehabilitation" accounts for 0.3% of National Institutes of Health (NIH) research funding from 2006 to 2011. The combination of rehabilitation with other research areas pertinent to PM&R (ie, arthritis, stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, cerebral palsy, myasthenia gravis, muscular dystrophy, chronic pain, and fibromyalgia) accounts for only 1.4% of NIH grant funds during this 5-year period (<http://report.nih.gov/rcdc/categories/>). This level of funding is out of proportion to the clinical and public health needs. In addition, much of this funding supports basic and clinical research, rather than research focused on the physical, social, and environmental contributors to disability [6].

There are few high-quality research studies; very few systematic reviews have been undertaken, and in many of those that have been conducted, the authors have found methodological flaws in the studies examined. Despite the involvement of rehabilitation in the care of so many areas of clinical practice, NIH consensus panels have commented that rehabilitation services are the most understudied area of clinical care [3]. As a result, in 2007, the Institute of Medicine suggested that greater emphasis be placed on evaluation of interventions to minimize activity limitations and participation restrictions, recommending that Congress increase appropriations for disability research to a level commensurate with the national need and "increase the visibility and coordination of disability research" [7].

## WHY SHOULD WE CARE?

The era of reimbursement for medical care based on experience and opinion is ending. We are entering an era that demands increased accountability, in which clinicians will be responsible for delivering services based on evidence. Although pharmaceuticals have long been held to a standard of proof of efficacy, procedural and behavioral interventions have not been held to a similar standard. For example, the Centers for Medicare & Medicaid Services (CMS) requires proof of drug efficacy to be eligible for reimbursement under Part D. Similarly, the move towards "pay for performance" or "value-based purchasing" will likely entail insurance coverage for health care that meets performance measures for quality and efficiency, on the basis of evidence of comparative effectiveness and cost. If there is insufficient evidence, people with functional limitations or disabilities may experience restricted access to or even elimination of rehabilitation services. For these reasons, systematic data collection and

analysis to assess outcomes of care is essential to our future ability to provide care that we believe to be effective and valuable. We are also interested in mechanistic research that identifies contributors to function and disability. These contributors may be separate from contributors to disease and mortality.

## CHALLENGES TO REHABILITATION RESEARCH

To adequately address the current needs for rehabilitation research, it is imperative to first consider some of the challenges. These relate to the (1) nature of the specialty, (2) the grading systems for determining best evidence, (3) the definition of valid standardized outcome measures, and (4) the low number of trained researchers and funded studies. Funding tends to cluster around diagnostic groups, not impairments and functional limitations. This delineation creates additional challenges for those who research pain, fatigue, or performance rather than a specific disease.

### Unique Focus of PM&R

The focus of PM&R is human function and participation. In contrast with research that focuses on a tissue or organ (eg, a drug to improve heart function), it may not be possible to blind subjects to rehabilitation interventions, and there is no single measurement that can be used to assess human function and participation. Therefore, the breadth and complexity of rehabilitation, small sample sizes because of the need to individualize treatment, an inability to blind subjects or use a placebo control (eg, rehabilitation program or medical device), and the difficulty assigning an ethical and practical control group (ie, who not to provide with rehabilitation) have all been barriers to generating high-quality evidence.

### Grading of Evidence

These challenges, in the context of the evidence standards and methods used in many systematic reviews, have contributed to reviews of evidence in PM&R in which the authors conclude that very little or no Level 1 evidence exists [2]. Such results may reflect a dearth of well-controlled rehabilitation studies rather than a lack of intervention effectiveness. The double-blinded RCT is the most rigorous research design for assessing efficacy because of the researcher's ability to determine cause and effect while avoiding spurious causality and bias that is inherent in other research designs. A multitude of RCTs have been conducted to evaluate community and behavioral interventions in the fields of psychology, nursing, public health, and other fields, indicating that this design is possible to apply more frequently than it has been in rehabilitation research. Therefore, in testing rehabilitation

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