David Tulsky Abstract:

New Outcomes Measurement Systems for Biomechanics and Rehabilitation Research

Traumatic brain injury (TBI) and traumatic spinal cord injury (SCI) are associated with a broad constellation of physiological changes and secondary medical complications that significantly impact patients' health-related QOL (HRQOL]. They have seen a rapid increase in the number of clinical trials designed to restore functioning or improve secondary conditions following a traumatic injury. However, the traditional outcomes have not kept pace with the science as the traditional scales often use generic patient reported outcome measures which lack the sensitivity and specificity needed to detect meaningful differences in rehabilitation intervention research.

Since 2004, several institutes from the National Institutes of Health have shared a mutual vision to re-engineer and revolutionize the way patient-reported outcome (PRO) tools are created, selected and employed in clinical research and practice. The Patient-Reported Outcomes Measurement Information System (PROMIS, funded as a grant within the NIH Roadmap Initiative) and Neuro-QOL (funded as a contract from the NINDS to measure quality of life in neurological disorders) are two large scale initiatives that promise to re-shape outcome measurement in NIH funded research. Subsequently NIH, the National Institute on Disability and Rehabilitation Research (NIDRR), and the Department of Veterans Affairs Rehabilitation Research & Development Program (RR & D) have all provided funding to bring this work to rehabilitation medicine, with particular focus on spinal cord injury and traumatic brain injury research.

This presentation will provide an overview of the advances in measurement that are on the horizon that promise to greatly enhance biomechanical rehabilitation research in the years to come. A description of advanced statistical methods like Item Response Theory and advanced technological advances like Computerized Adaptive Testing will be presented. Additionally, the presentation will demonstrate how content validity can be greatly enhanced through extensive qualitative research to identify key issues in relevant patient groups. Finally, the presentation will present a method of linking scales targeted to specific population groups (e.g., SCI and TBI) with large scale generic instruments developed by the NIH. Finally, the PROMIS, Neuro-QOL, SCI-QOL, SCI-CAT, and TBI-QOL measurement systems will be discussed.
These efforts should improve the state of the science of rehabilitation research and can, potentially, be used as Common Data Elements across funding agencies to facilitate cross study comparisons.