Inaccurate Evaluations Used to Assess Individuals with ME/CFS

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Introduction

ME/CFS is a disease with different subtypes, varying severity of symptoms, and fluctuation of symptoms and activity levels. Unfortunately after several years, ME/CFS still remains puzzling and poorly understood by healthcare professionals. This is due mainly to the absence of standard diagnostic criteria. Furthermore, current methods used to access the physical capabilities of persons afflicted with this illness rely primarily on functional capacity evaluations (FCEs) that measure only the occurrence of symptoms and nothing more.

Such methods do not provide information on the severity of symptoms, the fatigue, the fluctuations of symptoms and activity level, and severity of symptoms that occur over time. This type of approach results in an unreliable portrayal of the true complexities and the interrelations among symptoms. Therefore, by inaccurately reflecting the fluctuating nature and variability of this debilitating illness, current FCEs do not capture the true nature of this disease. In addition, sincerity of effort is often examined. If the person is reluctant to carry out any items during the testing process, they may be wrongly branded insincere and malingerers.

FCEs and Sincerity Testing - Unfortunately employers, lawyers and insurers are relying more heavily on data acquired from FCEs prior to making decisions on reimbursement in disability claims, on planning treatment for rehabilitation, and on readiness to return to work. These tools are supposed to define an individual's functional abilities or limitations in the context of safe, productive work tasks. Furthermore, some tests are used to detect the "sincerity of effort exhibited by the participant to perform optimally at the time of evaluation. An insincere effort is defined as one in which the participant deliberately gives less that a full effort during physical testing.

Functional Capacity Evaluations - Current issues associated with the use of FCEs are: qualifications of the evaluators; reliability and validity of the tests; length of assessment; projection of endurance to 8-hour workdays; standards of practice; selection of FCE; and safety protocols.

General - FCEs are currently used to contain healthcare costs, reduce the amount of time and money spent on rehabilitation, and determine whether a claimant has wage-earning potential in litigation based on the participant's tested physical abilities. There a great number of FCEs available and in use. They vary widely in the number measurements obtained, degree of standardization, clarity of the concepts and underlying theories, variety in choice of measuring

instruments, and adequacy of measurement for certain injury groups. Thus, no one test is totally comprehensive for one or a great number of situations.

Qualification of Evaluators - Occupational and physical therapists appear to be the primarily healthcare professionals to perform FCEs. They have the background and training to evaluate function, analyze performed-tasks, and understand disease pathology and the musculoskeletal system. Currently, other healthcare professionals are involved in the administration of FCEs including chiropractors, nurses, athletic trainers, vocational evaluators, physical therapy assistants, exercise physiologists, psychologists, kinesiologists and physicians. Given the variation in skill levels among these disciplines, evaluator training should be required to for an individual to become a "certified evaluator". Certification would ensure quality and consistency in evaluation, scoring and report writing related to FCEs. All FCEs on the market provide training, but there is variance in how the training is delivered, i.e., train-the-trainer or individual certification of each administrator. Therefore, certified administrators will vary in knowledge and competence depending on their experience background and the type of training preparation undertaken.

Furthermore, beyond training on administration and evaluation, several assessors have emphasized the importance of logical and clear reporting of observations that are easy to read and free of jargon. The report should provide the reader with a clear picture of the participant's physical capabilities and limitations as they relate to the critical demands of his/her job. This would include input from both employer and employee, and compare the participant's status of functional capability with the requirements of the job vacated. This practice is not done.

Reliability and Validity of Test - The purpose of the FCEs is to provide "objective" data high in reliability and free from examiner bias. Reliability studies of FCEs are performed on subjects without disabilities. The reliability of FCEs on individuals seen in clinics is unknown. Therefore, caution should be exercised when conclusions are based on these tests results or extrapolations made from these results. Such extrapolations may be highly misleading, for example, it is determined that a person with ME/CFS who does the paperwork associated with the test procedure for 3 hours can work at a desk for 8 hours. In reality, the person may do nothing but rest for the next day after the 3 hours of testing, because the activity led to exhaustion. In many cases, the reliability and validity of FCEs have not been documented in published peer-reviewed research journals.

Validity is an essential requirement for all measurements. A score is considered valid if it measures the properties that it purports to measure and can be used to make inferences. In FCEs this means a score predicts real-world function. Establishing validity is more difficult than establishing reliability due to the prediction aspect. External factors such as the work environment, work level of

performance, and work schedule may affect the participant's level of performance and ability to return to work. Once again, a lack of peer-reviewed publications on the validity of FCEs leaves their validity open to question.

Length of Assessment - The time taken to administer FCEs varies. Some take less than 2 hours whereas others take 2 days for administration. Literature indicates that 4-6 hours are required to assess general work demands, e.g., lifting, carrying, reaching, sitting, standing, walking, hand strength and coordination. Those who favour a 2-day test indicate that this duration leads to the greatest accuracy because it allows for retesting on day-2.

Projection of Endurance - Performance exhibited on a FCE conducted over a few hours does not reflect the participant's endurance for a full-day's work schedule. Specific formulas for projecting performance to an 8-hour workday are not available. Each person has a unique set of physical capabilities that cannot be generalized through generic formulas that would thus be subject to inaccuracy. Documentation of heart rate, endurance factors (e.g., oxygen consumption, blood pressure and respiratory rate), changes in body mechanics and fatigue can be helpful in such a projection. Literature suggests that participants should not be required to exceed a cardiovascular effort of 65% of their maximum heart rate. Individuals with ME/CFS are incapable of and should not do aerobic activity as it leads to damage to mitochondrial DNA. This reduces the person's ability to carry on aerobic activity even more and the individual's condition could be made worse.

Standards of Practice - This means the development of a clear set of procedures for administering and scoring tests. Under these circumstances, administration and scoring should not change regardless of the person conducting the assessment. No such standard exists as yet.

Selection of FCE - Many tests lack comprehensiveness, therefore, there is no single most appropriate test for any one client or any one assessment situation. No one assessment can provide all the answers concerning work injury and return to work.

Safety Protocols - There is little reference in the literature to the inclusion of fitness evaluations in FCEs. These should be conducted in order to assess the physical limitations of the participant. It is left to the examiner to administer each task with no knowledge as to what harm it may cause

- Injury can occur when the participant is asked to perform at a level of maximum voluntary effort. There are two schools of thought on this issue:

- intervention by the assessor decreases the test's validity and reliability; and

- No intervention by the assessor places the participant at an unacceptable risk of injury.

Sincerity of Effort - Reliability and Validity - Despite the widespread use of methods to detect the sincerity of participant's efforts during clinical assessment, little is found in the literature addressing reliability and validity of measurements using this method. Until research on these methods is reported in peer-reviewed literature, clinicians should avoid basing evaluation of sincerity of effort on such tests. For example, a person afflicted with ME/CFS may feel all right and have energy on the day of the examination. It would look as if the individual was faking. This would not give a true picture of the ill person's capabilities.

Clouded Terminology - The understanding of biobehavioral factors affecting recovery are clouded by the terms "symptom magnification" and "exaggerated pain
behavior". These two terms are frequently used in evaluation reports by clinicians. Neither term can scientifically be measured and therefore should be avoided.

Self-limiting Behavior - Participants can give less than a full effort during physical evaluations for a variety of reasons: pain due to musculoskeletal dysfunction; ..fear of pain; fear of re-injury; ..anxiety; .depression; lack of understanding of instructions; lack of understanding of the importance of the test, and ..secondary financial gains.
If self-limiting behavior predominates during an FCE, lack of sincerity of effort may be inferred and reported.

Waddell's Nonorganic Signs - These are nonorganic clinical signs, e.g., tenderness of nerve roots. They are not intended for use in detecting sincerity of effort or malingering, however, they are used frequently in clinical practice to imply sincerity of effort or an exaggeration of symptoms. For example, the tenderness test may be used and contribute to the erroneous classification of participants requiring further psychological assessment when their primary problem with pain stems from organic sources other than nerve roots. In addition, techniques of test administration, e.g., amount of pressure exerted in tenderness test, are not standardized. This can lead to variability of testing and scoring the nonorganic signs. Therefore, statements regarding sincerity of effort cannot be supported through application of the Waddell's Nonorganic Signs.

Documentation of Pain Behavior - In reports of musculoskeletal evaluation or FCE of participants, clinicians frequently document that participants have "exaggerated" pain behavior. Pain behavior is only one aspect of the complex experience of pain. Failure to include measures that address other cognitive and psychosocial variables that affect the pain experience may result in an incomplete assessment and inappropriate treatment.

Muscle Performance Tests - There is no correlation between sincerity of effort and consistent effort during testing. Measurements not substantiated in the literature but frequently used by clinicians as an indication of lack of sincerity are: coefficient of variability; musculoskeletal evaluation and FCE; and grip measures. None of these approaches has been supported in the literature as reliable and valid measures of sincerity of effort.

Relationship of Heart Rate to Pain Intensity - The premise is that heart rate increases directly as pain increases and when participants report high pain scores without increase in heart rate, it is concluded that they are exaggerating their pain. There has been no correlation between increased pain and increased heart rate and increased rate of respiration in the literature.

Clinical Implications - The concept of sincerity of effort is illusive and difficult to measure. If judgements based on currently available methods, clinicians are taking great risk of incorrectly classifying some people as malingerers and insincere. Such unwarranted conclusions violate the tights of those tested.

There is a Better Way - Current measures to assess ME/CFS such as FCEs and sincerity of effort do not consider either the severity of symptoms nor their fluctuations in symptom severity and activity level that occur over time. The test results will reduce the probability of clear understanding of the complexities of the illness.

Instead, one piece of current research suggests a better approach to provide an accurate picture of the complexities of this illness. It involves the combination of a self-reporting scale and a devise called CSA actigraph to measure the frequency and intensity of activity. This devise is capable of measuring the intensity of activity and recording values at 1-minute intervals through the day and night for 22 consecutive days. The implication of this assessment system is that it captures the symptom dynamics and variability involved in ME/CFS.