

Outcome Oriented

The Online Newsletter of the
Center for Outcome Measurement in Brain Injury (COMBI)

Winter 1999

COMBI Update

As of 11/1/99, the COMBI website has had more than 23,000 visitors. Lately, the COMBI has been getting between 2,000-3,000 visitors per month. On average 6,000 pages of information are reviewed in that amount of time (50 megabytes of information and graphics).

The most recent addition to the COMBI is the Coma/Near Coma Scale (CNC) created by Dr. Maurice Rappaport. The CNC scale was developed to measure small clinical changes in patients with severe brain injuries who function at very low levels characteristic of near-vegetative and vegetative states. Find out more about the CNC Scale at: <www.tbims.org/combi/cnc>

The COMBI will be presented as a poster at the 1st Federal Interagency Conference on Traumatic Brain Injury-Traumatic Brain Injury in the 21st Century: Learning from Models of Research and Service Delivery. December 2-4, 1999 at the Hyatt Regency Bethesda in Bethesda, Maryland.

The COMBI is coordinated by Santa Clara Valley Medical Center and is funded by the US Dept. of Education, Office of Special Education & Rehabilitative Services (OSERS), National Institute on Disability and Rehabilitation Research (NIDRR).

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Medicare PPS for Rehab Functional Related Groups using the MDS-PAC

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In 1983, Congress enacted the Medicare Prospective Payment System (PPS) for Acute Hospitals based on 490 DRG's (Diagnostic Related Groups). Rehabilitation Hospitals and Units were offered a temporary exemption from the Medicare DRG's and exemption criteria were established. Rehab Hospitals and Units have since been paid on a Medicare costs basis up to a Tax Equity and Fiscal Responsibility Act (TEFRA) limit, which was established during their first year of exemption. These TEFRA limits have ranged from \$11,000 - \$72,000 based on established operating costs. The exclusion of Rehabilitation Hospitals and Units from the Medicare PPS DRG's was intended to be temporary until the Health Care Financing Administration (HCFA) could develop an appropriate Prospective Payment System for rehabilitation Medicare patients. HCFA has approved the Minimum Data Set (MDS) - Resource Utilization Groups (RUG's) classification for skilled nursing facilities, and Functional Related Groups (FRG's) using the MDS-Post Acute Care (MDS-PAC) and a modified version of the Functional Independence Measure (FIM) for acute rehab providers. There are 65 FRG's which are based on the patient's impairment, age, FIM Motor and/or FIM Cognitive score. The FRG's and MDS-PAC are to be implemented by October, 2000. These changing and divergent Medicare payment systems will have a dramatic impact on the delivery of acute rehab, skilled nursing, and post acute services.

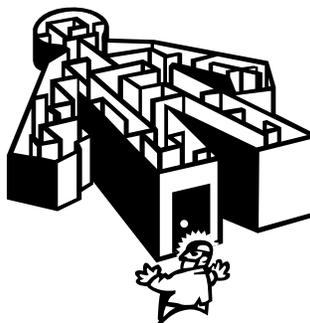
The proposed MDS-PAC contains over 250 data elements, including a modified version of the FIM, which all acute rehab providers would be required to collect and submit along with UB 92 billing information on all Medicare rehab patients. Although the description of most of the modified

FIM items are basically the same, the rating scale is very different. A reversed 7 point rating scale is proposed for the Self Care and Mobility items, a 6 point rating scale for Bowel & Bladder Continence, and a 5 point scale for Cognitive and Communication items. Functional assessments are to be made on day 4, 11, 60, and at discharge

reflecting a 3 day summary of performance. In addition to these functional status items, there are a considerable number of items in the MDS-PAC requiring documentation and information that acute rehab providers do not typically track. Many of these items are totally irrelevant to Acute Rehab patient populations. HCFA's intent is to eventually compare the case-loads, outcomes, and costs of care between acute rehab providers,

skilled nursing, and subacute facilities offering rehabilitation services. HCFA plans to release the Proposed Rules and Regulations regarding the MDS-PAC on December 1st in the Federal Register, allowing for a 30 day comment period. Rehab providers are urged to carefully review the proposed MDS-PAC items immediately to determine what data is currently available in their facilities in the required format, what additional forms, supporting documentation, computer program modifications and interfaces would be required, and the estimated costs of collecting and submitting all items in the proposed MDS-PAC. **Be prepared to respond to the public comment period in December.** Although most acute rehab providers support the concept of FRG's, they do not support the dramatic operational changes which would be required to collect all of the proposed MDS-PAC items.

Federal Register announcements can be reviewed online at <www.access.gpo.gov/su_docs/fedreg/frcont99.html>



The GOS vs. the DRS: Two Recent Papers

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The Glasgow Outcome Scale (GOS) is one of the most widely used measures in brain injury research. It is a five level classification scale: Good Recovery; Moderately Disabled; Severely Disabled; Vegetative; and Dead. Its strengths lie in its ease of administration (in many instances you do not need to personally see the subject) and its near universal acceptance. The main criticism of this scale is that the categories are too broad and do not allow discrimination of important clinical change. For example, Severely Disabled describes a situation where an individual only needs help with upper body dressing. It also describes a situation where someone can speak a few purposeful words, but cannot do any activities of daily living and needs constant supervision.

The Disability Rating Scale (DRS) is also a widely used outcome measure after brain injury. The DRS consists of eight items (eye opening, verbal response, motor response, cognitive ability for feeding, cognitive level for toileting, cognitive ability for grooming, level of functioning, and employability) which sum from 0 (no disability) to 29 (extreme vegetative state). Its value lies also in its ease in administration and in its presumed increased sensitivity over the GOS. Two recent papers have challenged the notion that the DRS is more sensitive than the GOS. The first, by Choi et al (1998), investigates the use of both the GOS and DRS as endpoints in a clinical trial. The second, by Pettigrew et al (1998), compares the GOS with the Barthel Activities of Daily Living (ADL) Index and the DRS three to twelve months post-injury.

CHOI ET AL, 1998

Choi chooses to equate sensitivity with smaller variability, stating that the smaller the variability the greater the sensitivity of detecting an equivalent change. He examines DRS and GOS data (at 3 and 6 months post-injury) by use of a coefficient of variation (standard deviation divided by the mean) as well as by distribution of scores. In both cases he finds the GOS more sensitive. In both cases the conclusions are questionable. First, Choi's use of the coefficient of variation to determine sensitivity is not appropriate. It is not correct to calculate means or standard deviations from an ordinal variable such as the GOS, because it implies that the scale is interval in nature, which it is not. Most individuals in a Rehab setting fall into the single category of Severely Disabled because they require some sort of assistance. Most individuals after Rehab fall into one of three categories (Severely Disabled, Moderately Disabled or Good Recovery). If you were to ignore the ordinal nature of the GOS you would find that it has less variability. But this argument is akin to using a categorical scale of "Young" or "Old"



rather than a person's age. Of course you would expect less variability with the categorical variable. But that does not mean that the category is as descriptive. In this paper, 89 subjects were described as having Good Recovery on the GOS. Using the DRS with the same subjects, 41 of those subjects (46%) actually had mild to partial disability. Which scale is losing important clinical information?

Second, Choi is also concerned that within the Severely Disabled and Vegetative categories of the GOS there are wide variations in associated DRS scores. In some cases there are overlapping DRS scores across GOS categories. In other words there is a subject in the Severely Disabled GOS group that scored worse on the DRS than some subjects in the Vegetative GOS group. Some overlap could be expected but certain ratings in Choi's are concerning. Two individuals were in the GOS Vegetative category but had DRS scores of 4-6. This is not possible. Using the GOS definition of Vegetative, the minimum DRS score an individual could have would be 23 (see box below). Five of the eighteen (28%) ratings of GOS Vegetative have DRS scores less than 23. There are other areas where DRS ratings are questionable as well, significantly weakening the conclusions from this paper.

PETTIGREW ET AL, 1998

Pettigrew compares GOS and DRS data on eighty subjects between three and twelve months post-injury. She found that the ratings by the GOS described more problems than the DRS. Specifically, she found that of the 27 subjects that scored a 0 on the DRS, eleven or 41% scored a Moderate Disability on the GOS. Pettigrew's rationale for this finding is that these individuals had no problems returning to work, but did have restrictions with recreational activities and/or interpersonal relationships. Pettigrew finds that in this instance the GOS is more sensitive. She makes a valid point, the DRS is not as sensitive in its extremes, and was not designed to take into consideration the ability to perform recreational activities or participate in interpersonal relationships. However, the GOS exhibits a similar insensitivity. Examining the 35 individuals rated as Severe Disability on the GOS, 43% rated as moderately disabled on the DRS, 49% rated moderately severe, and 8% rated severely disabled. On this end of the spectrum the DRS appears to be more sensitive.

These two papers, supporting the use of the GOS over the DRS, appear to have significant flaws. Which outcome measure would you use?

Choi S, Marmou A, Bullock R, Nichols J, Wei X, Pitts L: Primary end points in phase III trials of severe head trauma: DRS versus GOS. *J Neurotrauma* 15:771-6, 1998.

Hall K, Mann N, High W, Wright J, Kreutzer J, Wood D: Functional measures after traumatic brain injury: Ceiling effects of the FIM, FIM+FAM, DRS, and CIQ. *J Head Trauma Rehabil* 11:27-39, 1996.

Jennett B, Bond M: Assessment of outcome after severe brain damage. A practical scale. *Lancet* 1:480-484, 1975.

Pettigrew L, Wilson J, Teasdale G: Assessing disability after head injury: Improved use of the Glasgow Outcome Scale. *J Neurosurg* 89:939-43, 1998.

GOS & DRS Comparison: What is Vegetative?

GOS Vegetative: No evidence of meaningful responsiveness. Reflex responses in limbs. Cannot obey simple commands or utter any words.

DRS minimum for this state is 23

Eye: 0 (*Spontaneous*)

Communication: 3 (*Incomprehensible*)

Motor: 3 (*Flexing*)

Feeding, Cognitive Ability: 3 (*None*)

Toileting, Cognitive Ability: 3 (*None*)

Grooming, Cognitive Ability: 3 (*None*)

Function: 5 (*Totally Dependent*)

Employability: 3 (*Not Employable*)

Recent Scales in the Literature

The measures described below are not part of the COMBI but have been recently described in the literature.

Psychosocial Outcome Risk Indicator (PORI)

The PORI is a screening/assessment instrument made up of 18 questions, each having a 4-point scale. It addresses the following areas: financial strain, post-injury stressors, social support, access to resources, sense of mastery, pessimism/optimism, motivation, blame/anger, personality and behavioral changes, legal issues, and positive appraisal. A professional (social worker) makes an assessment on the likely impact each factor will have on the individual or his/her significant other. It is not an interview scale. Reliability was assessed with comparison to a self-completed form of the PORI. Results compared favorably with those of the General Health Questionnaire (GHQ), General Function sub-scale of the Family Assessment Device (FAD-GF), and the Problem Checklist (PCL).

Watts R, Perlesz A: Psychosocial Outcome Risk Indicator: Predicting outcome following traumatic brain injury. *Brain Injury* 13:113-124, 1999.

Community Outcome Scale (COS)

The COS was designed to discriminate between impairments/disability and handicap, reflecting how responsive a community is to problems faced by individuals with disabilities. It is based on categorizing individual problems and how these problems/issues impact community outcomes. The scale has four dimensions: social integration, mobility, occupation, and engagement. Subjects and their families are asked to describe current problems and strengths/solutions. Responses are examined in light of the four dimensions. Each dimension is then rated from 0 to 6. A score of 0 would be no problem, or fully compensated. A score of 5 would mean that customary environment/activity is almost totally inaccessible, with no options offered that would improve the situation. A score of 6 would be that the individual is no longer living in the community. The scale was validated with the Hospital Anxiety and Depression Scale (HAD) and with items from the Functional Independence Measure+Functional Assessment Measure (FIM+FAM).

Stilwell P, Stilwell J, Hawley C, Davies C: Measuring outcome in community-based rehabilitation services for people who have suffered traumatic brain injury. *Clin Rehabil* 12:521-31, 1998.

United Kingdom Functional Assessment Measure (UK FIM+FAM)

The United Kingdom FIM+FAM Users Group has worked to ensure consistent ratings on the FIM+FAM between different centers in the UK. Ten 'troublesome' items from the original FIM+FAM were identified, revised, and tested. Raters were tested individually as well as in teams in accurate rating of vignettes. Raters used newly devised decision trees for completing the UK FIM+FAM. Accuracy increased for individuals from 74.7% to 77.1% and for teams from 83.7% to 86.5%. Details of the revised items are given in the paper. The complete scale is available from the author.

Turner-Stokes L, Nyein K, Turner-Stokes T, Gatehouse C: The UK FIM+FAM: Development and evaluation. *Clin Rehabil* 13:277-287, 1999.

Levels of Cognitive Functioning Assessment Scale (LOCFAS)

The LOCFAS is an adaptation of the Rancho Levels of Cognitive Functioning Scale (LCFS) that converts the narrative description for LCFS levels one through five into a behavioral checklist. Subjects at LCFS levels of five or lower are not suitable candidates for neuropsychological assessment, but can be described through use of this scale. Forty-one individual behaviors are laid out on a grid. The grouping of behaviors guides the clinician in making the assessment. Test-retest reliability was satisfactory; concurrent validity at initial assessment and discharge was assessed with the Disability Rating Scale (DRS), Glasgow Coma Scale (GCS), Stover-Zeiger Scale (S-Z), and Expanded GOS (EGOS). Predictive validity at admission was assessed using the GCS, S-Z, EGOS, and DRS at discharge.

Flannery J: Using the Level of Cognitive Functioning Assessment Scale with traumatic brain injury in an acute care setting. *Rehabil Nurs* 23:88-94, 1998.



CURRENT COMBI SCALES

Listed below are the current COMBI scales, as well as the contributing center.

Agitated Behavior Scale (ABS),
Ohio Regional TBI Model System

Coma/Near Coma Scale (CNC),
Santa Clara Valley Medical Center (SCVMC)

Community Integration Questionnaire (CIQ), The Rehabilitation Institute of Michigan

Disability Rating Scale (DRS),
SCVMC

Functional Assessment Measure (FAM),
SCVMC

Functional Independence Measure (FIM™), SCVMC

Glasgow Outcome Scale (GOS), SCVMC

The Rancho Level of Cognitive Functioning Scale (LCFS), SCVMC

Mayo Portland Adaptability Inventory (MPAI), The Mayo Foundation

Neurobehavioral Functioning Inventory (NFI), Medical College of Virginia

The Patient Competency Rating Scale (PCRS), MossRehab TBI Model System

Supervision Rating Scale (SRS), The Institute for Rehabilitation Research (TIRR)

More information on these scales at:
<www.tbims.org/combi>.

Future Directions

The COMBI will continue to add new measures and act as a resource for the rehabilitation community. Additional instruments will include the American Brain Injury Consortium (ABIC) GOS, the Satisfaction With Life Scale (SWLS), and the Craig Handicap Assessment and Reporting Technique (CHART).

An article describing the COMBI will be included in the February 2000 edition of the Journal of Head Trauma Rehabilitation.

Please email us at <combi@tbi-sci.org> with your thoughts and suggestions. Let us know how we measure up!

Outcome Oriented is a project of the Center for Outcome Measurement in Brain Injury (COMBI) which is funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), National Institute on Disability and Rehabilitation Research (NIDRR).

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This document is available online at:

<www.tbims.org/combi/combinews.html>

COMBI: WORLDWIDE DISSEMINATION



Shaded areas represent visits from users from countries around the world. Twenty percent of COMBI visitors connect from countries outside of the United States.

ATTENTION! TBI in the 21st Century Conference!

The TBI Model Systems and the National Institute on Disability and Rehabilitation Research, United States Dept. of Education are pleased to present the

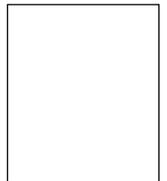
1st Federal Interagency Conference on Traumatic Brain Injury
December 2-4, 1999 at the Hyatt Regency, Bethesda, Maryland

Conference topics include: Prevention and Epidemiology; Acute Care; Rehabilitation; Living with Traumatic Brain Injury; Special Topics

For additional information download the PDF version of the Conference Brochure (671K) <www.kmrrec.org/tbimsc99.pdf> or the Conference Registration Form (15K) <<http://www.kmrrec.org/tbimsc99reg.pdf>>.



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