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Nicholas J. Cioe

Assumption College, nj.cioe@assumption.edu

Gary S. Seale

Centre for Neuro Skills

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TITLE

Brain Injury Rehabilitation Outcome Measurement: Challenges and Future Directions

AUTHORS

Nicholas J. Cioe, Ph.D., CRC, CBIST
Assumption College

Gary S. Seale, Ph.D., LPA, LCDC
Centre for Neuro Skills

1 The Brain Injury Association of America (BIAA) published a position paper
2 (<http://www.biausa.org/biaa-position-papers.htm>) that describes the state of outcomes research in
3 the field of brain injury and identifies the factors to consider when evaluating existing studies
4 and embarking on future outcomes research. This commentary summarizes that paper by
5 highlighting three major challenges for outcome measurement in brain injury rehabilitation. It
6 also presents opportunities for improving outcomes research through improved research design,
7 standardization of measurement tools across the continuum with utilization of national databases,
8 and an evidence-based approach to providing care to help move brain injury rehabilitation
9 outcome measurement in a positive direction.

10 Outcome measurement in brain injury rehabilitation has progressed. The Interagency
11 Traumatic Brain Injury (TBI) Outcomes workgroup recommended the use of multiple measures
12 with sound psychometric properties that demonstrate utility with the brain injury population in
13 TBI outcomes research.[1] At a minimum, measures selected should assess global level of
14 function, neuropsychological impairment, psychological status, activity limitations and
15 participation restrictions, and perceived health-related quality of life. To accomplish this, most
16 rehabilitation programs employ multiple measures to assess function in several domains as part
17 of a comprehensive outcomes or program evaluation system.[2]

18 Despite this progress, there remain several major challenges for outcome measurement in
19 brain injury rehabilitation. First, there are no universally accepted outcome measurement tools.
20 Second, outcome measurement research has not translated to better predictability of outcome.
21 Third, most persons with brain injury do not have adequate funding to support access to the full
22 continuum of care necessary for value-based service delivery models.

23 **Absence of universally accepted outcome measurement tools used throughout the industry**

24 The World Health Organization’s (WHO) International Classification of Functioning,
25 Disability, and Health (ICF) provides a standard language and framework for the description of
26 health and health-related states. It classifies outcome measure in three domains: *impairment* (e.g.,
27 memory, attention, balance, swallowing, executive functioning, etc.), *activity limitations* (e.g.,
28 ambulation, eating, dressing, grooming, talking, etc.), and *participation restrictions* (e.g.,
29 working, volunteer, home maker, parent, etc.).

30 Consistent with the language of the WHO ICF, a number of global outcome measures
31 have been developed for the brain injury population and have demonstrated sound psychometric
32 properties, for example, the Mayo-Portland Adaptability Inventory and the Community
33 Integration Questionnaire. Likewise, a number of domain-specific measures have been
34 developed, such as the Disability Rating Scale and the Supervision Rating Scale. Unfortunately,
35 given the range of potential outcomes important to brain injury rehabilitation, particularly at the
36 post-acute level of care (i.e., ADL performance, community integration, employment, life
37 satisfaction and quality of life), there is no agreed-upon single measure or set of measures to
38 evaluate outcome following brain injury rehabilitation. In a survey conducted by the Brain
39 Injury Interdisciplinary Special Interest Group (BI-ISIG) of the American Congress of
40 Rehabilitation Medicine (ACRM) involving 49 community-based brain injury rehabilitation
41 programs across 23 states, little consistency was found in terms of outcomes measurement tools
42 used. Fifty-nine percent of programs surveyed employed the Mayo-Portland Adaptability
43 Inventory as an outcome management tool, but over 31% of programs reported using a “home
44 grown” measure. The authors concluded that the “absence of universally accepted outcome
45 measures limits the availability of a common language and the ability to benchmark against like
46 programs or define best practices for community-based treatment.” [3]

47 The Uniform Data System for Medical Rehabilitation (UDSMR), established in 1987, has
48 positively influenced outcome measurement at the acute care level, including the required use of
49 the Functional Independence Measure (FIM) as the primary tool for outcome measurement.
50 More than 600 articles have been published using UDSMR instruments and data, and the
51 research suggested that functional assessment could be developed into a science to provide the
52 knowledge for understanding the “biology of disability,” a term that implies possible dominant
53 (and therefore expected) response patterns to disability based on the biological, social, and
54 environmental factors that influence outcome. The “biology of disability” concept could help
55 clinicians distinguish patterns of expected functional limitations from unexpected functional
56 limitations.[9]

57 The required use of a single tool or set of outcome measurement tools, consistent with the
58 WHO ICF, from the point of discharge in an acute setting through the post-acute continuum of
59 care, would support the understanding of the biology of disability following brain injury.

60 OutcomesInfo, a web-based database system developed through National Institutes of Health
61 (NIH) Small Business Technology Transfer (STTR), maintains a national database platform to
62 support the collection of brain injury outcome measurement data. At this point, use of outcome
63 measurement tools supported by OutcomesInfo’s platform and submission of data to the national
64 database is voluntary.

65 **Outcome measurement research has not translated to better predictability of outcome**

66 The expectation is better measurement of outcome will allow for analyses that support a
67 better understanding of the factors that influence outcome. While true in theory, such analyses
68 require the ability to control for variables that influence outcome. Unfortunately, brain injury
69 rehabilitation outcomes research is characterized by vast differences in the demographics of

70 individuals who are injured and in their access to care, substantial heterogeneity in etiology,
71 severity, chronicity, and disease progression following injury, and important distinctions in
72 treatment settings, provider expertise, intervention types and intensities, and measurement
73 tools.[2]

74 Alone or in combination, each of the aforementioned variables can significantly impact
75 the outcome of brain injury rehabilitation [10] making it extremely difficult to perform research
76 studies that adequately control for these variables. The use of common outcome measurement
77 tools across the continuum of care (see Figure 1), and the entry of those outcome data into a
78 national database, would help provide a data set of adequate size and content to support research
79 that can identify practices to improve outcome predictability.

80 **INSERT CONTINUUM OF CARE (Figure 1) HERE**

81 **Inadequate funding to support access to the full continuum of care necessary for value-**
82 **based service delivery models**

83 Although there remains significant room for improvement in brain injury rehabilitation,
84 adequate knowledge and tested clinical interventions exist to treat brain injury effectively for
85 improved outcome. [4-8] However, few individuals who sustain a brain injury have access to the
86 full array of services along the TBI continuum of care (as depicted in Figure 2). Given the
87 numerous variables that influence outcome and the often unorganized and inaccessible array of
88 services along the continuum, it is extremely difficult to compare one brain injury outcome to
89 another. Consider the difference in outcome between former Congresswoman Gabby Giffords
90 and an 18-year-old gang member. While both experienced a bullet wound to the head during an
91 assault, the many pre-existing and injury related variables (e.g., age, pre-injury education level,

92 SES, length of loss of consciousness, treatment access) must be considered before treatment
93 related factors can be reliably analyzed.

94 An alternative approach to outcome research would allow each person who receives a
95 brain injury to access a coordinated array of services along the continuum of care during which
96 time a standardized set of data is collected. By standardizing – in so much as providing the
97 proper treatment intensity for the appropriate duration at the right time in the right setting (see
98 Figure 2) – the treatment experience, individual demographics and heterogeneity in etiology,
99 severity, chronicity, and disease progression can be analyzed to provide better outcome
100 predictability.

101 **INSERT OUTCOME = ILLUSTRATION (Figure 2) HERE**

102 The current political landscape supports health care service delivery that maximizes
103 value, that is, improved health outcomes for the money spent. Brain injury services can be
104 extremely expensive making them a prime target for criticism and funding restrictions. Unlike
105 treatment for a torn knee ligament, there is not a widely accepted and adequately funded course
106 of treatment following brain injury. The absence of such inhibits a meaningful and accurate
107 value-based analysis of services.

108 The field of brain injury rehabilitation continues to develop. Increased appreciation for
109 the moral and ethical responsibility to allocate adequate resources to support post-acute care
110 should help improve access to the full continuum of care. Commensurate attention to improving
111 interventions, improvements in imaging, and increased knowledge about genetic factors should
112 help move best practice forward. There is a sense among leaders in the field that the future is
113 bright.

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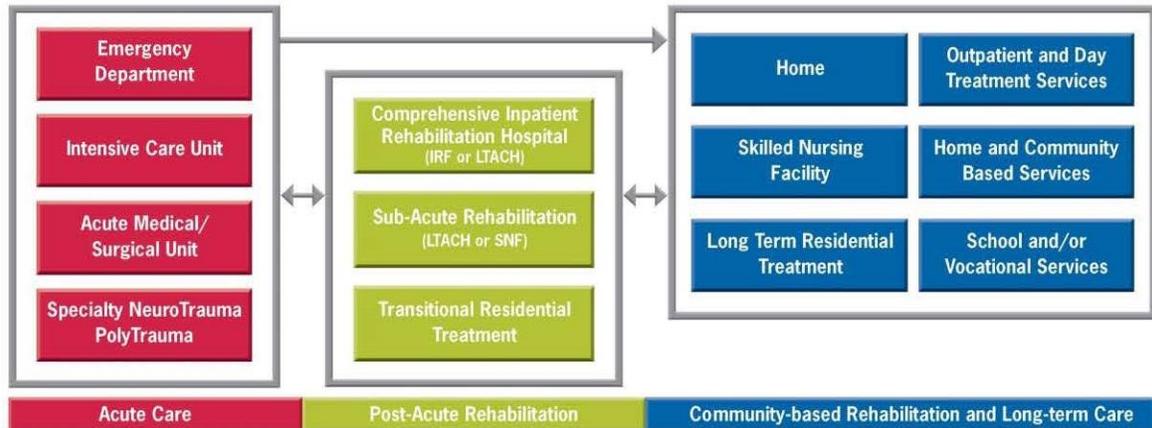
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ILLUSTRATIONS

Figure 1

Traumatic Brain Injury Continuum of Care



Developed by H. Reyst for The Essential Brain Injury Guide 5th Edition (p. 13)

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Figure 2



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