OUTCOME MEASURES IN BRAIN INJURY REHABILITATION.

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Abstract

Brain injury rehabilitation services require competent measures of outcome to monitor the progress made by individuals in their care. The FIM + FAM is the measure most widely used for this purpose. However, research suggests that this measure contains a number of limitations and does not adequately assess the activity limitations and participation restrictions experienced by individuals who have suffered brain injuries. The current study examined five outcome measures (BICRO-39, MPAI-4, R-CHART, CIQ, and DRS) for their suitability as possible replacement measures at Cavit ABI in Wellington and Auckland. Ten participants with brain injuries (eight males, two females; seven with TBI, three with injuries due to stroke) were administered six different outcome measures by therapists at Cavit ABI centres in Wellington and Auckland on admission and again at six weeks into the rehabilitation programme. Outcome measures were examined in relation to a set of specified criteria, and feedback regarding the performance of each outcome measure was collected from each therapist using a staff questionnaire. The results of the study show that there does not seem to be one adequate outcome measure currently available for use within post-acute brain injury rehabilitation settings. Although the FIM + FAM was found to contain a number of strengths particularly in assessing physical independence, the MPAI-4 was found to be more useful in identifying goals related to activity limitations and participation restrictions, which was the key area of focus.

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Chapter 1:
Overview

The purpose of the present study is to examine a range of measures for their suitability for assessing change in activity (disability) and participation (handicap) after brain injury rehabilitation. Participants will have received rehabilitation at Cavit ABI (Acquired Brain Injury) Rehabilitation, a private rehabilitation service situated in Lower Hutt and Auckland, providing specialised rehabilitation to clients who have sustained an acquired brain injury through either the effects of stroke or a traumatic brain injury (TBI).

The study developed from a request made by staff at Cavit ABI for an evaluation of commonly used outcome measures, based on a concern that the measures currently being used were not quite measuring the constructs of interest. Efficient and valid outcome measurement is an important component of service provision as it provides feedback to the service regarding individual needs and progress towards fulfilling those needs.

Internationally, the most widely used measure of outcome is currently the Functional Independence Measure and Functional Assessment Measure (FIM + FAM). A number of limitations however have been identified with the measure. These include a strong orientation to structure and function (impairment), which has little relevance in rehabilitative settings; that it is very long and confusing to score; and that it is less than ideal for measuring outcomes (Turner-Stokes, 1999; Hobart, Lamping, Freeman, Langdon, McLellan, Greenwood, & Thompson, 2001).

The FIM + FAM is currently used as an outcome measure by Cavit ABI and considered by staff to be unsatisfactory. The current study then aims to compare the FIM + FAM with other outcome measures. Using a pre-test, post-test design, six different outcome measures will be completed regarding those receiving rehabilitation at Cavit ABI. As well as statistical analysis of the information about measures, subjective data will be collected from the therapists at these centres, regarding their impressions of the practical utility of each of the six measures.

It is anticipated that the study will result in identification of a valid and reliable outcome measure for assessing activity limitation and participation restriction for use at Cavit ABI. In doing so, the conclusions made will also act as a guide for other rehabilitation agencies, who are searching for alternative outcome measures.

The current investigation will be preceded by a discussion of brain injury with an emphasis on mild, moderate and severe TBI and on the common outcomes resulting from brain injuries and stroke, and the domains of functioning that may be affected (Chapter 2). These are the components that a new outcome measure must be capable of assessing adequately.

Chapter Three provides an overview of rehabilitation, in particular addressing the models of rehabilitation relevant to rehabilitative practices in New Zealand. These models include the International Classification of Impairment, Disability and Handicap (ICIDH) and the International Classification of Functioning (ICF) as well as those models pertinent to the NZ Disability Strategy and ACC legislation.

Chapter Four provides a review of the outcome measures for brain injury rehabilitation that are currently available. Including the FIM + FAM, nine outcome measures are examined, with the strengths, weaknesses and psychometric properties being discussed for each. Six outcome measures were eventually chosen for inclusion in this study.

A brief review of the issues initially raised in Chapter One, but developed in the light of the introductory chapters, is provided in Chapter Five leading to specific objectives and hypotheses. Method, results and discussion are presented in Chapters Six to Eight respectively. Limitations that may have hindered the study findings, and directions for future study regarding outcome measures in brain injury rehabilitation are included in the discussion.

Chapter 2:
Brain Injury

Brain injuries may be due to a large number of conditions, but are most often due to either traumatic brain injury (TBI), or cerebrovascular accident, otherwise known as stroke. The Head Injury Society of New Zealand report that each year an estimated 9000 people are admitted to New Zealand hospitals with head injuries (Turner, n.d.). Additionally, according to the Stroke Foundation of New Zealand, everyday at least 19 people in New Zealand have a stroke, which equates to almost 7000 cases per year ("Stroke statistics," n.d.). The current chapter will briefly examine the definitions of TBI and stroke, common methods used to rate severity, and the domains of functioning that can be affected by these injuries.

Traumatic Brain Injury

A traumatic brain injury (TBI) is defined by the National Head Injury Foundation (1985) as "an insult to the brain, not of a degenerative or congenital nature, but caused by an external force, that may produce a diminished or altered state of consciousness" (Rose & Johnson, 1996, p. 1). A brain injury is also generally classified into three groups depending on the severity: mild, moderate, and severe. Severity is generally diagnosed using three particular concepts. Firstly, the length of time a person remains unconscious after a head injury can give an indication of how severe the injury is (Lucas, 2000). For example, if loss of consciousness (LOC) is less than 30 minutes, the injury is considered mild. However, if the LOC lasts for longer than 30 minutes, the injury is considered to be moderate to severe (Lucas, 2000).

The second measure of severity is the length of post-traumatic amnesia (PTA). For a mild injury the PTA should be less than one hour, while PTA between one and 24 hours is classified as moderate, and severe injuries can involve PTA lasting for longer than a 24-hour period (Lucas, 2000).

Finally, the Glasgow Coma Scale (GCS) remains the most commonly used instrument for measuring brain injury severity in a clinical setting (Fischer & Mathieson, 2001). This instrument uses a scale from 3 to 15 to rate verbal, motor, and eye-opening responses (Lucas, 2000). High scores represent a better outcome. Therefore, a mild injury will incur at least 13 points; a moderate injury, 9-12 points; and a severe injury will score less than 8 points (Fischer & Mathieson, 2001).

The severity classification given to an injury has implications for treatment. For example, a case of mild injury may be examined by hospital staff and then discharged without being admitted to hospital. However it is common for symptoms such as nausea, headaches, dizziness, fatigue, and impaired concentration and memory to remain for a number of weeks. This is known as post-concussion syndrome (Powell, 1996). Those with moderate injuries are more likely to be admitted to hospital, overnight at least. Again many symptoms may remain for a significant time, these include those stated above, as well as cognitive difficulties (i.e., problems with thinking, attention span, planning, organizing, and word finding) and anxiety (Powell, 1996). In the case of severe injuries, hospitalisation may be prolonged and may be associated with physical deficits including loss of the ability to walk, speak, or use fine motor skills. According to Powell, (1996), individuals with severe injuries are most likely to require and receive post-acute rehabilitation.

Trauma to the brain can occur in a number of different ways. For example, injuries may be diffuse (due to acceleration/deceleration forces), or focal and may involve skull fractures, and intra-cranial haemorrhage (Smith, 1996). Closed head injuries occur when the brain is not penetrated by an object (Lucas, 2000). Rapid acceleration or deceleration can cause the soft mass of brain to hit areas of the skull with force, and the axonal tracts contained in the white matter may be damaged due to rupturing and stretching (Smith, 1996).

Penetrating head injuries are generally known as open head injuries, as they occur when a person has received a blow to the head and often involve an object piercing the skull (McDonald, Togher, & Code, 1999). Depending on the velocity of the object, the damage to the brain may only be focused around the entrance path of the object (Lucas, 2000). Generally, a penetrating head injury will result in the damage of brain matter and intra-cranial bleeding (Lucas, 2000). However, ischaemia, edema, and infections in the brain may also result as secondary effects (Kay & Lezak, 1990). Secondary effects can result at a later stage after the initial brain insult (Smith, 1996).

Stroke

Stroke is a form of cerebrovascular disorder and has been defined by the World Health Organization (WHO) as “a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” (Wolfe, 2000, p. 276). There are two main classifications of stroke with the basic premise for each, being that damage occurs when an area of the brain either does not receive enough blood supply or receives too much. These classifications are obstructive ischaemic strokes, and haemorrhagic strokes (Shannon, 2003).

Ischaemic strokes are the most common type and occur when a clot blocks a blood vessel in the cerebral arterial system, or the brain receives an insufficient blood supply (hypoxia) (Shannon, 2003). There are three types of ischaemic strokes – cerebral thrombosis; cerebral embolism; and hypoxia (Weinstein & Swenson, 2000). Clots may be made up of coagulated blood, fat deposits originating from blood vessel walls, bacteria, gas bubbles, or narrowing and hardening of the arteries (Weinstein & Swenson, 2000).

Haemorrhagic strokes occur due to “bleeding that occurs within brain tissue”, as well as outside the brain (Subarachnoid/Subdural haemorrhage) (Shannon, 2003, p. 35). A number of factors may cause the haemorrhage, including blood disorders, toxins, hypertension, and congenital cerebral artery defects (Weinstein & Swenson, 2000).

Stroke is diagnosed using radiological findings (e.g., angiography’s, MRI, CT Scan), cerebrospinal fluid analysis, and clinical examinations (Patel, Coshall, Rudd, & Wolfe, 2003). The clinical examination involves testing a number of important aspects. For example, a neurologist will examine higher cognitive functioning and will look for a number of physical symptoms including numbness, paralysis of the face or limbs, visual defects, dizziness, impaired coordination, and impaired speech (Weinstein & Swenson, 2000).

Domains of Functioning

The damage caused by both Stroke and TBI can result in a range of physical and cognitive impairments. For example, TBI is more likely to result in persistent headaches, dizziness, memory and concentration problems, and personality changes, than stroke. While stroke may produce numbness or paralysis of the limbs, and difficulty speaking more often than TBI, but is also associated with memory difficulties. The following section will examine the domains of functioning typically affected by an acquired brain injury.

Attention and Concentration Disorders.

TBI: Damage to many different areas of cortical and sub-cortical brain systems may result in attentional dysfunctions, therefore the incidence of attention impairments is very high in TBI (Cohen, Malloy, & Jenkins, 2000). Cohen and colleagues (2000), define attention as "enabling people to respond to particular information while either consciously or unconsciously ignoring other potential stimuli…Attention implies cognitive or behavioural withdrawal from some things so that others can be effectively dealt with" (p. 542).

Attention deficits due to TBI affect competency in many other areas, including sensory registration, memory, and perception (Cohen, Malloy, & Jenkins, 2000). It is also common for impairments to have implications for following social interactions (e.g., conversations), undertaking leisure activities (reading, watching television), and engaging in productive employment (Arciniegas, Adler, Topkoff, Cawthra, Filley, & Reite, 1999).

Stroke: Again, the incidence of attentional deficits is relatively high for stroke, particularly individuals who have sustained right hemisphere lesions (Lincoln, Majid, & Weyman, 2001). The mechanism behind attention dysfunction in stroke is much the same as TBI with the same implications for task endurance and memory competence (Leeds, Meara, Woods, Hobson, 2001). Studies have shown that attentional deficits may also play a role in the success of motor recovery after stroke (Hyndman & Ashburn, 2003).

Memory.

TBI: The most common outcome of TBI is impairment to memory. One American study reports that between 54% and 84% of all individuals with TBI suffer from memory dysfunction (DeLuca, Schultheis, Madigan, Christodoulou, & Averill, 2000).

Initially, TBI may result in retrograde amnesia or anteriograde amnesia. Retrograde amnesia is the loss of memory for events occurring before the TBI was sustained. Anterograde amnesia pertains to the loss of memory for a time after trauma to the brain (Lovell & Franzen, 1994). For both types of amnesia, memories may or may not gradually return.

Damage to particular areas of the brain may also result in difficulties with acquisition, encoding, storage, and/or retrieval of information (DeLuca, et al., 2000). Deficits in such areas will affect a person's ability to learn new material and can make it difficult to complete day-to-day tasks such as remembering to carry out instructions or meet appointments. This can mean that successful employment prospects are minimized and dependency on others is necessary (Quemada, Cespedes, Ezkeura, Ballesteros, Ibarra, & Urruticoechea, 2003).

Stroke: Memory impairments may occur in up to 30% of all stroke cases (Wade, 1988). Research has shown that posterior lesions to the brain can result in impairments to short-term memory (Shannon, 2003). Long-term memory may also be affected by stroke, particularly if anterior lesions are present (Delaney & Ravdin, 1997). Further, deficits to information processing systems in the brain can make encoding new information very difficult (Delaney & Ravdin, 1997).

Executive Functioning.

TBI: Individuals who have sustained a moderate to severe TBI, particularly to the frontal lobes, often exhibit impairments to executive functioning (Lovell & Franzen, 1994). Our executive functions are those that allow us to develop and activate a plan, identify any consequences, and modify accordingly (Bamdad, Ryan, & Warden, 2003). However, if executive functioning has been damaged, an individual may experience problems in goal formulation and planning, goal-directed behaviour, and effective performance (Lovell & Franzen, 1994). These executive difficulties may be manifest as irritability, excitability, impulsiveness, erratic carelessness, and rigidity (Leon-Carrion, Alarcon, Revuelta, Murillo-Cabezas, Dominguez-Roldan, Dominguez-Morales, Machuca-Murga, & Forastero, 1998).

Without the ability to formulate and carry out a plan, accomplishing simple daily tasks may be too much for an individual with TBI. This may result in the diminished ability for self-care and independence, as well as the reduced probability of success in employment (Bamdad, Ryan, & Warden, 2003).

Stroke: The implications of executive functioning deficits for stroke are much the same as for TBI. However, perseveration, disinhibition, and rigidity may be more common manifestations (Leeds, Meara, Woods, & Hobson, 2001). Perseveration pertains to "the inability to terminate a sequence of behaviour" (Lovell & Franzen, 1994, p. 683). Disinhibition can result in displays of impulsive and improper social behaviour (Bamdad, Ryan, & Warden, 2003), while rigidity produces inflexibility in attempts at task completion (Leeds, Meara, Woods, & Hobson, 2001).

Emotional and Behavioural Dysfunction.

TBI: Various emotional problems may result from damage to different areas of the brain. For instance, lesions in the left hemisphere can lead to depression, while damage in the right hemisphere may produce an impaired expression of emotions with regard to intensity, frequency and appropriateness (Starratt, 2000). The most common emotional difficulties, as pointed out by Starratt (2000), include: "diminished emotional expression; excessive emotional expression; spontaneous, unprovoked, intense expression of emotion; and unprovoked expression of fear or intense anxiety" (p. 618).

Trauma to the brain can result in a number of personality changes and/or behavioural difficulties. These include irritability, impulsiveness, emotional lability, amotivation, insensitivity, apathy and aggression (Kant, Duffy, & Pivovarnik, 1998). Depression is often a common outcome of TBI. Das-Gupta and Turner-Stokes (2002), report that around 26% of all TBI cases will suffer from depression as a result of the trauma. Furthermore, sexual disinhibition may also be an issue (Rothwell, La Vigna, & Willis, 1999).

Stroke: A number of emotional difficulties may result from stroke including anxiety, depression, and high levels of frustration and anger. Many of these emotional changes may be due to "natural responses to the psychological trauma of stroke" (Shannon, 2003, p. 281). However damage to the brain can also result in specific behavioural changes and emotional disturbances. For example, the incidence of clinical depression following stroke is relatively high, with one study reporting a prevalence of between 25% and 79% (Gordon, & Hibbard, 1997, cited in Zorowitz, Gross, & Polinski, 2002).

In fact a condition termed 'post-stroke depression' is common among stroke survivors, which is a form of post-stroke mood disorder (Robinson, 2003). Studies have shown that post-stroke depression is linked to lesions in the left anterior region of the brain, and particularly in the basal ganglia (Herrmann & Walesch, 1993; Robinson, Starr, & Price, 1984, cited in Robinson, 2003). In comparison to general diagnoses of depression, the characteristics of post-stroke depression include a stronger incidence of extreme agitation, hyper-emotionalism, and mood swings (Robinson, 2003).

Furthermore, emotional lability is common after stroke, where an individual may laugh, cry, or become angry for no obvious reason (Shannon, 2003). A diminished expression of emotions is also often the outcome of stroke (Starratt, 2000).

With regard to behavioural changes after stroke, depression and emotional lability may cause an individual to act differently. Also, deficits in judgement may lead to poor decision-making, which may result in an individual appearing to behave irresponsibly (Shannon, 2003). It has also been observed that pre-morbid personality characteristics may become amplified after a stroke (Guilmette, 1997).

Communication Difficulties.

TBI: Effective communication can be impaired by TBI, although this is not as common or as profound as with stroke. Factors such as perception and expression, prosody production, and the ability to recognise emotional situations, may produce difficulties with communication (Borgaro, Prigatano, Kwasnica, Alcott, & Cutter, 2004). Research has shown that difficulties with affect can cause significant problems for long-term psychosocial reintegration, and individuals may be at an increased risk of social isolation (Borgaro, Prigatano, Kwasnica, Alcott, & Cutter, 2004). Damage to specific areas of the left hemisphere of the brain may also result in Wernicke's aphasia or Broca's aphasia (Lovell & Franzen, 1994).

Stroke: Shannon (2003) reports that 25% of stroke patients will experience impairments to language functions. Further research has shown that stroke is more likely to produce affective perception deficits as an outcome of communication (Borgaro, Prigatano, Kwasnica, Alcott, & Cutter, 2004). Aphasia is also a common result of stroke, especially after ischaemic stroke when the left hemisphere of the brain is damaged in some way (Beeson & Rapcsak, 2000). This impairment affects word selection, language production, and language comprehension, in spoken as well as written language (Beeson & Rapcsak, 2000). Obviously deficits in these areas can seriously affect an individual's ability to communicate effectively with others. This can lead to social withdrawal and reduced employment opportunities.

Mobility.

TBI: The mobility of an individual after TBI may be affected in a number of ways. Although more severe impairments to motor functioning are uncommon, difficulty balancing and coordinating movements have been reported to affect at least 30% of all individuals after TBI (Basford, Chou, Kaufman, Brey, Walker, Malec, Moessner, & Brown, 2003).

Spasticity and paresis are possible outcomes of TBI affecting mobility, particularly if there are lesions to the upper motor neurones of the corticospinal tracts (Hankey, 2002). Spasticity is defined as "a velocity-dependent increase of tonic stretch reflexes (muscle tone) with exaggerated tendon reflexes" (Hankey, 2002, p. 291). It can cause muscles to stiffen and spasm painfully, and movement of limbs may be difficult to control (Shannon, 2003). Individuals suffering from spasticity due to TBI may have as a result "a tight fist, a bent elbow, an arm pressed against the chest, stiff knee and, or a pointed foot that can interfere with walking"(Shannon, 2003, p. 343). Therefore everyday tasks may be difficult to complete independently. Injuries to upper motor neurons may also result in a condition called stiff-legged gait, which affects the ability to flex the knee (Kerrigan, Bang, & Burke, 1999). This can make walking very difficult.

The locked-in syndrome (LIS) is a very severe condition that may be caused by a lesion to the ventral pons area of the brain (Leon-Carrion, Van Eeckhout, Dominguez-Morales, & Perez-Santamaria, 2002). Individuals with this condition experience paralysis in the arms and legs and are unable to communicate using words or any body movements. Often individuals with LIS are only able to indicate awareness of themselves and their surroundings, using blinking and eye movements (Leon-Carrion, et al., 2002).

Stroke: One of the most common outcomes of stroke is hemiparesis, affecting between 73% and 88% of all stroke patients in America (Winstein, Rose, Tan, Lewthwaite, Chui, & Azen, 2004). Hemiparesis refers to "weakness to one side of the body" (Shannon, 2003, p. 279). A more severe outcome is hemiplegia, which refers to paralysis to one side of the body. Both of these impairments affect the opposite side of the body, to the site of the brain damage (Shannon, 2003).

Limb apraxia is also quite common after the event of a stroke. This is defined as "an inability to perform learned skilled movements with the forelimbs correctly" (Heilman, Watson, & Gonzalez-Rothi, 2000, p. 509). In general, someone suffering from apraxia may have difficulty planning and executing movements, particularly involving the use of tools or objects (Heilman, Watson, & Gonzalez-Rothi, 2000). However, specific apraxias may affect limb movement, ideomotor functioning, conduction and conceptual functioning (Heilman, Watson, & Gonzalez-Rothi, 2000).

Other impairments may include visual or sensory damage, dysphagia, or ataxia. Dysphagia refers to swallowing difficulties, while ataxia involves impaired coordination. Ataxia can result if damage occurs in the cerebellum and can leave an individual with difficulties walking, and maintaining balance and posture (Shannon, 2003). These impairments can leave a patient frustrated and very dependent on others for accomplishing everyday tasks.

All of the discussed domains of functioning affected by Stroke or TBI have a number of consequences relating to functioning in normal life roles and activities. The areas discussed above are considered to be structural and functional impairments, leading to activity and participation restrictions (or disabilities and handicaps), as suggested by the World Health Organisation (WHO). These are four areas that professionals working in rehabilitation generally aim to assess and improve in stroke and TBI patients. The following chapter will examine the roles of these professionals, and the models of rehabilitation that are relevant in New Zealand.

Chapter 3:
Models of Rehabilitation

Following brain injury or stroke, rehabilitation is a crucial step on the road to recovery. This process can be very complex, with the main aim being to "reduce handicap by optimising an individual's functioning through either the enhancement of the individuals skill repertoire or the modification of the environment in which she/he must function" (Alan, Finlayson, & Garner, 1994, p. 4). A number of health professionals are often involved in the rehabilitation process, with each formulating a unique plan of rehabilitation for the individual. Such a plan may require the participation of registered nurses, occupational therapists, physiotherapists, speech language therapists, neuropsychologists, social workers, and vocational placement personnel.

The current chapter will provide insight into the service provision of rehabilitation and the models of rehabilitation these services adhere to. Consequently, a short discussion covering the role of each professional enlisted in the rehabilitation process will follow. This is accompanied by a discussion of the health and legislation models shaping rehabilitation practices in New Zealand. These include the International Classification models developed by the World Health Organisation, the New Zealand Disability Strategy, and the Accident Rehabilitation and Compensation Insurance Corporation. This background will provide context to the setting in which the present study is set.

Professional Roles

Especially in the initial stages, nurses are required to cater to the persisting medical needs of the client. Although clients are generally medically stabilised before they begin rehabilitation, some medical needs often remain, whether this is due to the brain injury itself, or as a result of secondary injuries. For example, the evaluation of health status, and the distribution of medication are carried out by nursing staff, as well as evaluations regarding a client's general health care capabilities and the self-awareness of their condition (Guare, 1999).

A physiotherapist's role is to attend to the clients "ability to move and carry out activities" (Guare, 1999, p. 15). To do this, areas such as: mobility, gross motor coordination, strength and endurance, range of motion, motor planning, tone, sensation, posture, balance, and equilibrium; are all targeted with evaluations and specialized exercises (Guare, 1999).

In contrast, the occupational therapist's (OT) role in rehabilitation is focused around evaluating a client's ability to carryout activities of daily living. For example, aspects such as visuospatial and visuomotor functions, manual dexterity, upper extremity functioning, and sensorimotor integration are all thoroughly assessed (Guare, 1999). The OT will assist a client to adapt to possible new situations and increase independence with everyday tasks including budgeting, planning and problem solving (Powell, 1996). It is likely that some time will also be spent training a client to use specialized home adaptive equipment.

Oral motor skills and communication competence are areas of focus for the speech-language therapist. Communication is divided into four parts for assessment. These are phonology, semantics, syntax, and pragmatics and they are evaluated in terms of verbal expression, auditory comprehension, reading comprehension, written expression, and social communication (Guare, 1999). The functions producing swallowing reflexes are also the focus of evaluation within individuals (Guare, 1999).

The role of neuropsychological professionals is to conduct assessments into the cognitive and emotional capabilities of the client, and to implement relevant intervention strategies assisting with any neuropsychological deficits. Assessments are undertaken targeting higher cognitive functioning, which may include memory, attention, language, information processing, response speed, visuospatial skills, constructional skills, auditory and tactile perception, and perhaps academic abilities and personality (Guare, 1999). This collected information is then compared with available population norms. Specific interventions may be utilised for training a client to use alternative memory processing or information processing techniques. For example, using computer programmes or memory journals. A clinical psychologist may also be involved to evaluate emotional adjustment and coping, and to provide counselling.

Completing the rehabilitation team, the social worker involved will use their skills to assist families to obtain information pertaining to benefits, housing, accommodation, and transport options (Powell, 1996). These professionals can also provide clients and family members with counselling if required.

As part of the rehabilitation process, the services of vocational placement personnel may also be implemented. These personnel assist in "maximizing the individual's post-accident vocational development" (Blankenship, 1988, cited in Krollman & De Boskey, 1990, p. 208). Vocational rehabilitation takes the extent of a client's brain injury into consideration when finding suitable employment options. The aim is to find employment that is congruent with the client's skills and provides opportunity for earning an amount closest to the maximum earning capacity possible for the client with TBI (Krollman & De Boskey, 1990). Vocational assessment measures are utilised in order to assist with this process and to identify the employment goals of individuals with TBI (Thomas, 1990).

All of these professionals require high quality assessment measures to monitor the progress of their clients and each possesses a crucial role in the road to recovery for individuals who have suffered a brain injury. Although these experts may be regarded as individual entities, research has shown that methods of rehabilitation utilising an interdisciplinary rehabilitation model, produce greater long-term success in returning clients to near-normal levels of daily functioning (Khan, Baguley, & Cameron, 2003). Interdisciplinary rehabilitation services are those that aim for a team evaluation. Encompassing all of the objectives identified by the client and their family. In this way, data can be integrated from many disciplines to ensure that a detailed evaluation and treatment process is undertaken (Guare, 1999).

In order for this interdisciplinary process to be efficient, the professionals from various areas of expertise require similar guidelines by which to conduct their vocation. The following section provides a discussion of the models relevant to rehabilitation services in Aotearoa, New Zealand.

Models of Rehabilitation

The basic model that post-acute rehabilitative services adhere to, is different to the traditional care model used by hospitals and other medically based services. The traditional biomedical model focuses on the pathological diagnosis and the beneficial changes that occur in relation to this diagnosis (Kaplan, 2002). For example, Figure 3.1 shows how the emphasis is strongly focused around the impairment sustained by a patient (Hobbs, personal communication, 2003). Less attention is given to resulting disabilities while almost no concern for handicap is evident.

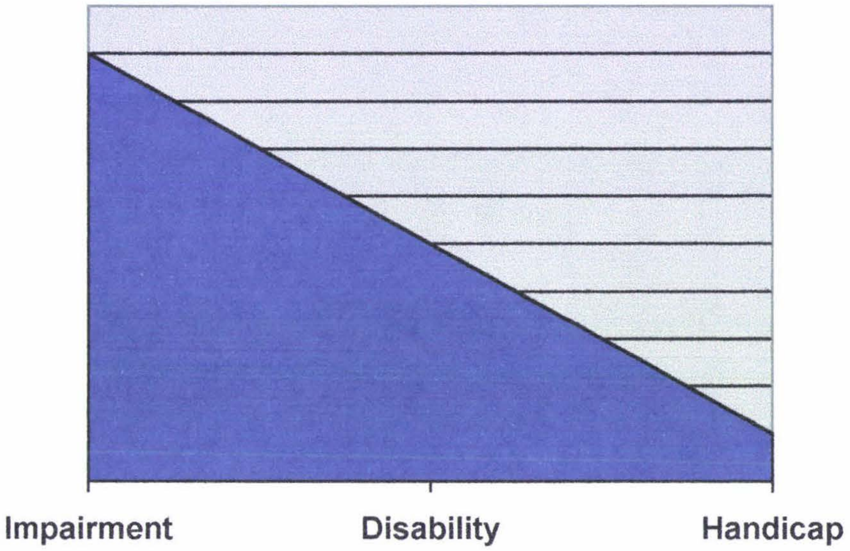

Figure 3.1: Traditional Biomedical Model

In comparison, the rehabilitation model, shown in figure 3.2, focuses most of its attention on handicap, with less focus on disability and impairment (Hobbs, personal communication, 2003). Consequently, it could be said that the rehabilitation model is focused more on quality of life (Kaplan, 2002).

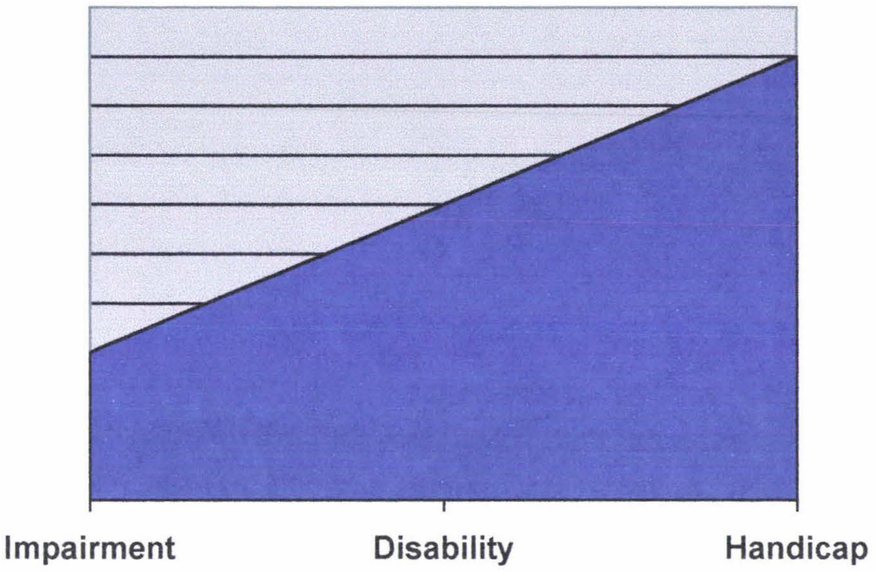

Figure 3.2: Model of Rehabilitation.

The terms impairment, disability, and handicap are used widely in rehabilitation literature. They come from the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) model, developed by the World Health Organisation (WHO) in the 1980's (Ustun, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). The WHO is a global organisation whose main goals are to oversee the management of trends assessment and to stimulate research and development (Yamey, 2002). This includes the "development and testing of new technologies, tools, and guidelines for disease control, risk reduction, health care management, and service delivery" (Yamey, 2002, p. 1296). WHO is also responsible for the development and oversight of the implementation of norms and standards (Yamey, 2002).

The ICIDH model was designed for the purpose of "seeking to contribute to the promotion of uniformity in broad concepts and terminology and, by indicating ways in which individual attributes may be grouped together for simplification, to encourage standardization and an improvement in the comparability of data" (Gray & Hendershot, 2000, p. 10). 'Impairment' refers to "abnormalities of body structure and appearance and with organ or system function, resulting from any cause" (Gray & Hendershot, 2000, p. 11). The term disability is defined as "any restriction or lack of ability, resulting from impairment, to perform an activity in the manner or within the range considered normal for a human being" (Smith-Knapp, Corrigan, & Arnett, 1996, p.

659). Finally, 'handicap' applies to the "disadvantages in normal role performances" (Hall & Johnston, 1994, p. 11).

Although the ICIDH model has been widely used around the world (including in New Zealand) since its creation, it was actually only meant for use in field trials (Ustun, et al., 2003). This was due to the existence of a number of flaws and limitations in the ICIDH (Ustun, et al., 2003). Owing to it's popularity, the WHO initiated a 10 year revision process, which resulted in the development of the ICIDH-2, later renamed the International Classification of Functioning, Disability, and Health (ICF) (Ustun, et al., 2003). The new model is based on both medical and social models of disability; integrating disease, trauma or health domains with social domains such as education, employment, and community life (Ustun, et al., 2003).

The ICF has renamed the three initial concepts (impairment, disability, and handicap) to be body structure and functioning, activity, and participation. The first of these terms refers to a number of specific impairments to body functioning and configuration, including mental, sensory, vocal, cardiovascular, respiratory, and digestive functions as well as categories of the nervous system (Gray & Hendershot, 2000). 'Structure and functioning' is defined as the "loss or abnormality of psychological, physiological, or anatomical structure or function resulting from illness or injury" (Malec, Moessner, Kragness, & Lezak, 2000, p. 670).

The 'activities' category is also more specific, referring to the "performance of person-level tasks or activities undertaken by the person" (Gray & Hendershot, 2000, p. 13). It supplies a list of eight 'domains of activity' that include learning and applying knowledge, movement, self-care, and communication. Gray & Hendershot (2000) stipulate, "activities are the observable and reportable performance of the actions of individuals in the context of their culture" (p. 13). Finally, 'participation' is defined as "an individuals involvement in life situations in relation to health conditions, body functions and structures, activities and contextual factors" (Gray & Hendershot, 2000, p. 13). There are nine participation domains, which include mobility, social relationships, education, economic life, and social and civic life (Gray & Hendershot, 2000).

The ICF has also corrected a number of other limitations of the ICIDH. For example, in designing the new model, cross-cultural and linguistic differences were taken into consideration; therefore significantly increasing its relevance to rehabilitation procedures worldwide (Ustun, et al., 2003). This obviously makes the model much easier to use. Additionally, the common language used in the ICF to describe functioning has been selected to allow efficient communication of information across a range of medical professions (Ustun et al., 2003).

Rehabilitation in New Zealand.

The New Zealand Disability Strategy: This strategy was developed as a document to promote the inclusion of all people in society, and particularly those with impairments (Ministry of Health, 2001). The goal is to create "a society that highly values the lives and continually enhances the full participation" of individuals with impairments and disabilities (Ministry of Health, 2001, p. 1). Obviously, this strategy is particularly important to the rehabilitation service, as the purpose of rehabilitation is to restore an individual to a level as close as possible, to that of 'normal functioning'. The Disability Strategy has fifteen objectives. These are listed in Table 3.1 below. All of these objectives are valuable to rehabilitation services in some way.

Table 3.1

Objectives of the Disability Strategy

	Disability Strategy Objectives
1.	To encourage and educate for a non-disabling society.
2.	To ensure rights for disabled people.
3.	To provide the best education for disabled people.
4.	To provide opportunities in employment and economic development for disabled people.
5.	To foster leadership by disabled people.
6.	To foster an awareness and responsive public service.
7.	To create long-term support systems centred on the individual.
8.	To support quality living in the community for disabled people.
9.	To support lifestyle choices, recreation and culture for disabled people.
10.	Collect and use relevant information about disabled people and disability issues.
11.	Promote participation of disabled Maori.
12.	Promote participation of disabled pacific peoples.
13.	Enable children and youth to lead full and active lives.
14.	Promote participation of disabled women in order to improve their quality of life.
15.	To value families, whanau and people providing ongoing support.

(Ministry of Health, 2001)

ACC: Another body set up to ensure that service providers are supplying an appropriate and efficient service is the Accident Rehabilitation and Compensation Insurance Corporation (ACC) under the Injury Prevention, Rehabilitation, and Compensation Act 2001 (IPRC Act) ("Vocational medical assessors guidelines," 2004). Since the majority of traumatic brain injuries are the result of an accident, this Act is certainly important in terms of the setting for the current study.

This IRPC Act places a strong emphasis on social rehabilitation, which "aims to restore a claimants functional independence and is provided through entitlements such as: aids and appliances (e.g. wheelchairs and walking frames); home help, childcare and attendant care; modifications to the home; and training for independent programmes" ("Vocational medical assessors guidelines," 2004, p. 5).

Under ACC, rehabilitation providers are also required to develop an individual rehabilitation plan for each patient claiming ACC who requires rehabilitation for a period of 13 weeks or more. As part of this plan, service providers must undertake assessments and supply specific outcome goals. Therefore the inclusion of outcome measures to monitor change, are a very important aspect of this plan. Meaning that rehabilitation services have an obligation to utilize adequate outcome measures in order to collect relevant client information.

The funding resources for stroke are not as straightforward. For example, ACC does not cover an individual who has suffered stroke unless it has been caused by a medical misadventure, or excessively strenuous working situations ("What does ACC cover," n.d.). In all other situations of stroke, the Health Board will provide general financial assistance. This funding is kept to a minimum, meaning that clients and their families are often required to pay for rehabilitation services (Foulsham, personal communication, 2004).

To summarize, all of the discussed models, pertinent to rehabilitative services in New Zealand, focus on increasing an individual's ability to function and participate within the community. Therefore, it is important for services to utilise evaluations specific for measuring outcome in this area in order to confirm that service goals are being achieved.

At present the Functional Independence Measure and Functional Assessment Measure (FIM + FAM) is the most widely used outcome evaluation (Turner-Stokes, 1999). However, this measure focuses primarily on disability and has been based on a more biomedical model, meaning that its suitability for measuring participation is minimal. The aim of the current study is to determine the suitability of the FIM + FAM in a rehabilitation setting in New Zealand while at the same time examining the suitability of other measures that might be acceptable replacements. The following chapter provides a review of currently available assessments and their potential for future implementation.

Chapter 4:
Review Of Outcome Measures

An initial review was conducted into the currently available range of outcome measures besides the Functional Independence Measure/Functional Assessment Measure (FIM + FAM), that focus on assessing activity (disability) and participation (handicap) within the setting of brain injury rehabilitation. This process revealed that very few outcome measures designed for this purpose actually exists, and those that did had identified limitations. More widely used measures that were of a higher quality (i.e., relatively high reliability and validity scores, fewer serious limitations, and the existence of empirical evidence supporting the usefulness of the measure), were selected for review and discussion. As well as the Functional Independence Measure (FIM) and Functional Assessment Measure (FAM), these measures included the Disability Rating Scale (DRS), the Community Integration Questionnaire (CIQ), the Revised Craig Handicap Assessment and Reporting Technique (R-CHART), the London Handicap Scale (LHS), the Hoensbroeck Disability Scale (HDSB), the Mayo-Portland Adaptability Inventory (MPAI-4), the Frenchay Activities Index (FAI), and the Brain Injury Community Rehabilitation Outcome Scale (BICRO-39). The strengths, weaknesses and psychometric properties will be discussed for each.

The Functional Independence Measure (FIM) & Functional Assessment Measure (FAM)

The (FIM), developed in 1984 by Granger, consists of 18 items (Ravaud, Delcey & Yelnik, 1999). These items cover areas of self-care, sphincter control, mobility, locomotion, communication and social cognition (Smith-Knapp, Corrigan, & Arnett, 1996). Each item contains between two and six components, and is measured using a scale from one to seven (Ravaud, Delcey, & Yelnik, 1999). Lower scores indicate a lower level of functioning. According to Ravaud and colleagues (1999), the FIM "was designed for use by clinicians or hospital managers for assessing degree of disability, evaluating functional gains, improving training and research methods, as well as measuring the cost/benefit ratios in rehabilitation" (p. 32). Adequate correlation scores of validity and reliability have been indicated for the FIM, including an inter-rater reliability score of 0.96 for the total FIM score (Smith-Knapp, Corrigan, & Arnett, 1996).

In 1989 the Functional Assessment measure (FAM) was developed to accompany the FIM, thus creating the FIM + FAM (Hobart, Lamping, Freeman, Langdon, McLellan, Greenwood & Thompson, 2001). The addition of the FAM meant that twelve new items were added to the original measure (Hobart, et al., 2001). These items were specifically included to create a measure that could be used for assessing brain injury (Hobart, et al., 2001). The seven-point scale was retained for this combined measure (Hobart, et al., 2001).

The FIM + FAM is reportedly the most widely and commonly used measure administered to assess disability (Turner-Stokes, 1999), and is the measure currently used by Cavit ABI Rehabilitation. However both the FIM and the FIM + FAM have a number of limitations. The most important is that they primarily measure disability and have little use in identifying participation restriction, or handicap (Turner-Stokes, 1999). Other limitations include the difficulty around scoring, uncertainty concerning the reliability, ceiling effects, and limited suitability for use with individuals within a clinical practice (Turner-Stokes, 1999; Hobart, et al., 2001).

The Disability Rating Scale (DRS)

This outcome measure was developed by Rappaport, Hall and Hopkins, et al., in 1977 (Zhang, Abreu, Gonzales, Seale, Masel, & Ottenbacher, 2002). The DRS attempts to cover all three of the ICIDH categories: structure/function (impairment), activity (disability), and participation (handicap), using four general categories and eight regions of functioning. These are: "Consciousness (eye opening, verbal response, motor response); cognitive ability (feeding, toileting, grooming); dependence on others; and employability" (Zhang, et al., 2002, p. 501).

The eight items of the DRS are rated by an observer using either a three or five-point scale (Zhang, et al., 2002). Total scores can range between 0 and 30, with high scores representing a low level of functioning (Zhang, et al., 2002). The DRS has been designed so that patient progress can be monitored over time (Zhang, et al., 2002). Studies have shown the DRS to be reliable and valid (Torenbeek, van der Heijden, de Witte, & Bakx, 1998). Inter-rater reliability correlations range between 0.97 and 0.98, while the calculated concurrent validity scores of the DRS range between 0.35 and 0.78 (Zhang, et al., 2002).

The reported limitations of the Disability Rating Scale include its failure to include specific items that could identify more conspicuous activity limitations resulting from brain injury, and that it shows ceiling effects (Malec, Moessner, Kragness, & Lezak, 2000). Also, it is considered that the need for observer-raters to judge client abilities poses as a downfall (Torenbeek, et al., 1998). However, as stated above, inter-rater reliability correlations are particularly favourable (Zhang, et al., 2002).

The Community Integration Questionnaire (CIQ)

The CIQ consists of 15 questions pertaining to "home integration (e.g., meal preparation, housework, childcare), social integration (e.g., shopping, visiting friends, leisure activities) and productive activity (e.g., full versus part time work, school, volunteer activities)" (Zhang, et al., 2002, p. 500). Each question is rated on a scale from 0 to 2 with higher scores indicating a higher level of community integration (Gurka, Felminghan, Baguley, Schotte, Crooks, & Marosszeky, 1999). This measure can be undertaken as a self-report assessment, although a significant other may give assistance (Doig, Fleming, & Tooth, 2001).

The CIQ has sound reliability, validity and internal consistency (Doig, Fleming, & Tooth, 2001; Gurka, et al., 1999). Studies have shown that test-retest reliability for the CIQ ranges between 0.83 and 0.97, while inter-rater reliability has been reported at 0.89 (Zhang, et al., 2002). Zhang and colleagues (2002) state that the CIQ may be one of the more appropriate measures available for assessing participation in the rehabilitation setting due to its consideration of "short attention span, fatigability, and memory problems of this population" (p. 507).

Despite these favourable correlational coefficients, several authors have outlined a range of limitations regarding the CIQ. Firstly, no appropriate studies have been undertaken to determine content validity or face validity (Dijkers, Whiteneck, & El Jaroudi, 2000). Secondly, this measure contains no means for the client to indicate whether they actually participated in any given activity (Doig, Fleming, & Tooth, 2001). Therefore, there is no way to tell if the client's lack of participation in an activity is due to disability, or due to personal choice. No attempt is made to determine potential environmental barriers either (Doig, Fleming & Tooth, 2001). Furthermore, Dijkers (1997, cited in Malec, Moessner, Kragness, & Lezak, 2000) states that the CIQ lacks normative data, has a lack of metric measurement consistency, fails to cover many of the conditions that may impair participation, and may have potential ceiling effects (p. 671). Also, the CIQ may contain bias, as some studies have shown that total scores for home integration and social integration are higher for women, while men's productive activities scores are higher than women's (Dijkers, Whiteneck, & El Jaroudi, 2000). Finally, the CIQ makes no attempt to measure pre-injury levels of activity (Doig, Fleming, & Tooth, 2001).

The London Handicap Scale (LHS)

The LHS was developed by Harwood, Rogers, Dickinson, and Ebrahim (1994) and contains only six questions, thus taking only a maximum of 15 minutes to answer (Harwood, et al., 1994). It may be filled in by the client, or answered using an interviewer (Dijkers, Whiteneck, & El Jaroudi, 2000). The questions cover 'mobility, physical independence, occupation, social integration, orientation, and economic self sufficiency' (Harwood, et al., 1994). The measure asks the client to compare himself or herself to someone in good health while responding to the questions.

This measure has reported favourable reliability and validity measures, including 0.80 for internal consistency, between 0.70 and 0.91 for test-retest reliability, and correlations between various other measures have produced scores between 0.31 and 0.78 for convergent validity. Construct validity is also high (Dijkers, Whiteneck, & El Jaroudi, 2000). Unfortunately, as yet no studies have attempted to determine the inter-rater reliability of the LHS (Dijkers, Whiteneck, & El Jaroudi, 2000).

The authors of the LHS caution against using this measure for assessing change in individual clients. Rather, it should be used for comparisons between groups (Harwood, et al., 1994). The LHS also contains terms that may bias against people with sensory impairments (e.g., seeing, speaking, and hearing) (Dijkers, Whiteneck, & El Jaroudi, 2000).

The Revised Craig Handicap Assessment & Reporting Technique (R-CHART)

Developed by Whiteneck, Charlifue, Gerhart, Overholser, and Richardson (1992), the R-CHART has been designed to assess physical independence, mobility, occupation, social integration, economic self-sufficiency & cognitive independence (Dijkers, Whiteneck, & El Jaroudi, 2000). It contains 32 questions covering these domains and is administered in the form of an interview, although it may be used as a self-administered questionnaire ("Introduction to the CHART," 2000). The R-CHART is scored using a one hundred-point scale for each of the six categories. A low score indicates a high level of participation restriction (Dijkers, Whiteneck, & El Jaroudi, 2000). The R-CHART has been designed to measure changes in a client's level of participation over time ("Introduction to the CHART," 2000).

The advantages of the R-CHART include the construction of the measure using criteria that is observable and objective rather than subjective (Whiteneck, et al., 1992). Test-retest reliability correlations are reported to be 0.93 for the overall R-CHART score, while correlations for each of the six categories range from 0.80 to 0.95 (Dijkers, Whiteneck, & El Jaroud, 2000). Also, Whiteneck and colleagues (1992) report that the R-CHART avoids many of the validity issues surrounding other handicap measures, due to its sole focus on participation, rather than both activity (disability) & participation (handicap).

The downside to the R-CHART is that it contains ceiling effects as clients may score top marks (indicating no participation restriction) on any dimension of the measure. However, Dijkers and colleagues (2000) suggest that this is not a disadvantage and is rather a reflection of instances where people's disabilities do not necessarily create participation restrictions.

The Mayo-Portland Adaptability Inventory (MPAI-4)

The MPAI-4 was designed for use with populations with brain injury, and is an extension of the original Portland Adaptability Inventory (Malec, Moessner, Kragness, & Lezak, 2000). It attempts to measure impairment, activity and participation using a wide range of items which cover "physical and cognitive capacities, emotions, adaptive and social behaviour, functional activities, and symptoms of psychiatric disorders and substance abuse" (Malec, Moessner, Kragness, & Lezak, 2000, p. 673). There are 30 items in total, which can be rated either by professional staff, the client themselves, or a significant other, using a four-point rating scale ("Overview of the MPAI-4," 2003). It is also possible to collect ratings from all parties to compare and combine ("Overview of the MPAI-4," 2003). A higher score on this assessment denotes lower levels of functioning. Studies have been conducted on inter-rater reliability, and these results have been favourable ("Overview of the MPAI-4," 2003). Other information on reliability and validity were not readily available.

Unfortunately, Malec and colleagues (2000) report that the MPAI-4 really only gives an indication of participation (handicap) in clients whose injuries to the brain are relatively mild. Additionally, it has been advised that certain item-rating scales require modification in order to improve the reliability and predictive validity of the measure (Malec, Moessner, Kragness, & Lezak, 2000). It has also been suggested that a number of items need to be removed due to their non-contributory relationship to the total score (Malec, Moessner, Kragness, & Lezak, 2000).

The Brain Injury Community Rehabilitation Outcome Scales (BICRO-39)

The BICRO-39 was developed in response to a need for a well-validated measure to assess outcomes after brain injury, and with the ICIDH model of rehabilitation in mind (Powell, Beckers & Greenwood, 1998). The authors Powell, Beckers and Greenwood (1998) explain that the BICRO-39 can be used in brain injury rehabilitation settings to assess pre-injury functioning, post-injury functioning, and also changes occurring over time. Separate rating forms are available for pre-injury and post-injury analysis, and for patient and carer responses (Powell, Beckers, & Greenwood, 1998). This measure contains 39 items that are focused around personal care, mobility, self-organization, contact with other people, socializing, employment, and psychological well-being.

Each of the 39 items is rated on a 6-point scale (0-5). High scores on this measure indicate activity and participation restriction (Powell, Beckers, & Greenwood, 1998). Test-retest reliability has been found to be high for the BICRO-39, with correlations reported between 0.70 and 0.98 (Powell, Beckers, & Greenwood, 1998). Construct validity and inter-rater reliability are also reported to be favourable (Powell, Beckers, & Greenwood, 1998).

The BICRO-39 requires further analysis in order to determine predictive validity (Powell, Beckers, & Greenwood, 1998). Additionally, the study undertaken to determine test-retest reliability involved a sample of only 25 respondents (Powell, Beckers, & Greenwood, 1998), therefore possibly affecting the validity of these results.

Research has also shown that some of the scales included in the BICRO-39 may possess ceiling and floor effects (Simpson, Secheny, Lane-Brown, Ferry, & Phillips, 2004).

The Hoensbroeck Disability Scale (HDSB)

This measure has been designed to assess "cognition, behaviour, activities of daily living, posture and movement, communication and personal and social functioning" (Torenbeek, et al., 1998, p. 308). There are 59 items in total, which are scored on either three-point, or five-point scales (Torenbeek, et al., 1998). A computer programme has been developed to convert individual item scores into a total score ranging between 0 and 100 (Torenbeek, et al., 1998). Low scores on the HDSB indicate low levels of functioning (Torenbeek, et al., 1998).

The advantages of the HDSB are that it has been designed to assess clients through observation, rather than opinion (Torenbeek, et al., 1998). The internal consistency and content validity of this measure is reported to be favourable, as well as the inter-rater reliability, with one study stating a kappa value of 0.70 (Torenbeek, et al., 1998). The Hoensbroeck Disability Scale is recommended to be used for treatment planning and team communication (Torenbeek, et al., 1998).

The drawback of this measure is that it focuses on disability and not handicap (Torenbeek, et al., 1998). A number of recommendations have been made for the HDSB, including a reduction in the number of items included in the scale, and a reconsideration of the scoring method (Torenbeek, et al., 1998). These changes would help to "decrease random variance, decrease the time burden on administration, and to improve clarity and communicability of the results"(Torenbeek, et al., 1998, p. 313). It has also been strongly advised that this measure needs further investigation into its sensitivity for change, and to assess discriminative power and predictive validity (Torenbeek, et al., 1998).

Frenchay Activities Index (FAI)

The Frenchay Activities Index has been developed by Holbrook and Skilbeck (1983) to primarily assess stroke rehabilitation (Carter, Mant, Mant, Wade & Winner, 1997), but has been used in other rehabilitation settings in the past (Dijkers, Whiteneck, & El

Jaroudi, 2000). It is administered in the form of an interview that is undertaken with either the stroke patient or a close family member or caregiver (Dijkers, Whiteneck, & El Jaroudi, 2000). With 15 items, these interviews take about 5 minutes to complete and cover various work and recreational activities (Dijkers, Whiteneck, & El Jaroudi, 2000). It is the frequency of activity participation within either three months or six months that is assessed, and total scores can range from 0 to 45 (Dijkers, Whiteneck, & El Jaroudi, 2000).

An advantage of the FAI is that is has been developed to assess the needs specific to elderly populations. Construct validity and convergent validity have shown strong correlations (Dijkers, Whiteneck, & El Jaroudi, 2000), along with inter-rater reliability that has been reported by one study to have a correlation of 0.90 (however this study had made changes to the frequency of activity timeframe by reducing it to a four week period) (Post & de Witte, 2003). There appears to be no available data on content validity of the FAI. A lack of studies into the FAI's clinimetric properties stands as one of its shortcomings (Post & de Witte, 2003).

Other criticisms of the Frenchay Activities Index include that elderly clients may be confused by the change that occurs in the frequency of activity time frame throughout the measure (from three months to six months). This factor also makes total score interpretation difficult (Dijkers, Whiteneck, & El Jaroudi, 2000). Furthermore, items on the FAI are not mutually exclusive. Therefore those answering the FAI have no way of distinguishing between, for example, "light and heavy housework, or between social outings and outings/car rides" (Dijkers, Whiteneck, & El Jaroudi, 2000, p. 75). Finally, although the FAI has been applied in other rehabilitative settings, there is no indication that it has been used to assess clients with traumatic brain injuries, thus reducing it's suitability to be included in the present study.

Conclusion

The nine instruments presented in this review each possess favourable characteristics as well as considerable flaws. Unfortunately, it is the case that as yet no completely satisfactory measure of participation within rehabilitation settings exists. It appears that the key reason for this is due to a lack of research into the operationalization of participation (or handicap) (Dijkers, Whiteneck, & El Jaroudi, 2000). Handicap is a very extensive concept and one of the major downfalls of participation restriction measures is that they only tend to focus on very confined aspects of participation (Dijkers, Whiteneck, & El Jaroudi, 2000).

The following table (Table 4.1) provides information regarding the domains of functioning covered by each measure presented above. Table 4.2, also presented below, identifies the criteria indicating characteristics of a competent outcome measure, and presents the ability of each of the nine measures in fulfilling these areas. Information regarding the existence of ceiling or floor effects is also presented in Table 4.2. Ceiling effects occur when the maximum score on a measure is too limiting to indicate an individuals true level of functioning. While floor effects occur when the minimum score is not low enough to indicate the true limits to functioning. Both tables use ticks to indicate the attributes that an outcome measure contains or covers.

Table 4.1

Domains of Functioning Held By Each Measure.

Domain	**FIM+ FAM**	**BICRO-39**	**MPAI-4**	**CIQ**	**DRS**	**R-CHART**	**LHS**	**HDSB**	**FAI**
Personal Care	✓	✓			✓	✓		✓	
Mobility	✓	✓	✓			✓	✓	✓	✓
Physical independence	✓			✓	✓	✓	✓	✓	✓
Communication	✓		✓		✓	✓		✓	
Social interaction &/or Participation in rec. activities	✓	✓	✓	✓		✓	✓	✓	✓
Family contact		✓	✓	✓		✓			
Emotional functioning &/or Adjustment	✓	✓	✓						
Cog. functioning	✓		✓		✓	✓	✓	✓	✓
Productive activity	✓	✓	✓	✓		✓	✓	✓	✓
Financial independence		✓	✓	✓		✓	✓		
Transportation	✓		✓			✓			

Table 4.2

Competency Criteria Held By Each Measure.

Measure	**Has Ceiling /floor effects.**	**Scoring is quick & simple**	**Identifies specific rehabilitation goals.**	**Allows for input from clients & their family's/ significant others.**	**Doesn't cause fatigue.**	**Measures change in functioning over time**	**No. of Questions.**
FIM + FAM	✓		✓			✓	30
BICRO-39	✓	✓	✓	✓		✓	39
MPAI-4	✓		✓	✓		✓	30
CIQ	✓				✓	✓	15
DRS	✓	✓			✓	✓	8
R-CHART	✓		✓			✓	32
LHS	✓	✓		✓	✓		6
HDSB	?	?	✓				59
FAI	?	✓	✓	✓	✓	✓	15

(? = Current research does not specify)

Nine outcome measures were presented to the service manager at Cavit ABI Wellington. In taking the current review into consideration, it was decided that the FIM + FAM, the R-CHART, CIQ, DRS, BICRO-39, and the MPAI-4 would be trialed during this study. Justification for the selection of these measures is provided in Chapter Six. Since Cavit ABI has used the FIM + FAM previously it was included as an obvious point of comparison, for the other five chosen measures.

Chapter 5:
The Present Study

At the outset of this study, the fulfilment of the objectives appeared fairly straightforward. That is, identifying an available outcome measure to replace the FIM + FAM appeared to be a simple task. However, in light of the review of currently used outcome measures, it became evident that an outcome measure encompassing all the required elements for a brain injury rehabilitation setting was difficult to locate. This is mainly because such a measure is required to fulfil specific attributes, such as covering appropriate domains of functioning that identify specific activity limitations and participation restrictions of individuals undergoing brain injury rehabilitation.

As has been stated, traumatic brain injury (TBI) and stroke can have a significant impact on the life of an individual, and their family. Common outcomes include memory and executive functioning deficits, emotional, behavioural and attention deficits, and problems with communication and mobility. All of these impairments can impact on an individual's ability to participate in activities and normal life roles. For example, personal care and everyday household tasks may be difficult to accomplish; roles as a partner or caregiver may change significantly with more dependence on others required; and recreational activities once enjoyed may be impossible due to physical and cognitive impairments. All of these may influence an individual's quality of life and may leave many feeling isolated and useless.

Rehabilitation aims to reduce the activity limitations and participation restrictions caused by stroke and brain injury outcomes, to allow individuals to enjoy greater independence and quality of life. To ensure that this is undertaken effectively, staff need appropriate information on which to base individualised goals.

The most widely used outcome measure in brain injury rehabilitation is the FIM + FAM. However, its substantial list of limitations suggests that alternative outcome measures could be highly beneficial to service providers. Therefore the objective of the present study is to attempt to compare and evaluate the FIM + FAM with other available and commonly used measures. The CIQ, DRS, R-CHART, BICRO-39, and the MPAI-4, are outcome measures containing certain qualities of interest and are to be assessed regarding their suitability for use within a post-acute rehabilitation setting. It was planned that all six of the outcome measures would be administered to participants, and a questionnaire be provided for the rehabilitation staff to complete. This questionnaire provides an opportunity for staff to comment on positive and negative aspects of each outcome measure involved in the study.

Aims of This Study

The main aims of the study are to ascertain:

(a.) The extent to which the respective measures are suitable for client groups of differing severities.
(b.) Whether a number of outcome measures may be used in conjunction with one another, to replace the FIM + FAM.
(c.) Whether outcome measure/s, alternative to the FIM + FAM, can be identified that are more useful than the FIM + FAM in identifying outcomes and measuring activity limitations and participation restrictions.

Hypotheses:

Staff Questionnaire Ratings.

1. Staff will rate the MPAI-4 as significantly better at identifying specific rehabilitation goals (on the grounds that it attempts to cover many key domains of functioning and has an easy to follow scoring system).
2. Staff will rate the DRS as significantly quicker and easier to administer (due to the small number of questions included in this outcome measure).
3. Staff will rate the BICRO-39 as easier for clients to understand in terms of layout and wording than other client self-rating forms (predicted because of the appropriate language used in this measure and the simple method of rating questions).
4. The DRS will be rated as producing significantly less fatigue for staff (this measure appears very brief to administer, only containing eight questions).
5. Staff will choose the MPAI-4 as a preferred measure (based on the prediction that this measure will competently identify goals of rehabilitation and because it incorporates many areas of functioning).

Measured Abilities.

6. The FIM + FAM will be significantly more sensitive at detecting change in functioning over time, than all other outcome measures tested (on the grounds that its seven-point scoring scale is more capable of detecting smaller changes in functioning).
7. Clients with mild to moderate brain injuries will show more change between time 1 and time 2 on the MPAI-4 than other measures (based on the research findings cited by Malec, Moessner, Kragness, & Lezak, 2000).
8. Clients with severe brain injuries will show more change between time 1 and time 2 on the BICRO-39 than other measures (based on the rating system utilised by this measure).
9. All outcomes measure will have ceiling and/or floor effects (predicted from the current research findings available on these outcome measures, which were presented in Chapter 4).

Chapter 6:

Method

Research Setting

This study was conducted at the Cavit ABI (Acquired Brain Injury) Rehabilitation centres in Wellington and Auckland. The service that Cavit ABI provides is an example of common rehabilitation service provision in New Zealand. These centres provide an interdisciplinary model of service provision with occupational therapists, physiotherapists, speech language therapists, nurses, social workers, clinical psychologists, and neuropsychologists working together to cater for the individual rehabilitation needs of inpatients. These inpatients have sustained mild, moderate or severe brain injuries due to TBI or stroke. Cavit ABI receives referrals nation-wide and clients are admitted as inpatients once they are medically stabilized.

The Wellington centre is currently situated in a hospital ward and can accommodate 12 clients at any one time, while Auckland provides four specialized houses catering for a total of 28 clients. Each house has been designed for a different purpose and caters for post-acute rehabilitation, neuro-behavioural rehabilitation, long-term rehabilitation, and for transition between rehabilitation and community reintegration. Both Auckland and Wellington centres provide permanent accommodation for a small number of inpatients.

The aim of the service is to co-ordinate a rehabilitation plan, fitting the specific needs of the individual, and to work towards identified goals, which encourage and develop the independence of the client. Each professional in the interdisciplinary team conducts their own assessment with the individual, and develops a rehabilitation plan that contributes to the overall goals of the rehabilitation team. One professional is allocated as the key worker for a client, which is determined by the most dominant rehabilitation requirements of the individual.

Participants

The criteria for participant inclusion for the study involved the following:

- The individual had sustained a mild, moderate or severe brain injury due to stroke or TBI.
- The individual had been referred to Cavit ABI in Auckland or Wellington for rehabilitation, during the data collection period of this study (5 months).
- The individual consented to taking part in the study.

The severity of the brain injuries sustained by individuals was determined using standard diagnostic criteria prior to the individual being referred to the rehabilitation service. These criteria include the length of time the individual was unconscious (30 minutes or more), the length of PTA (more than one hour), and the GCS score (a score of nine or more). The Disability Rating Scale (DRS) (Rappaport, et al., cited in Zhang, et al., 2002) has also been used for the purpose of this study to categorize the severity of an injury into mild, moderate and severe classes.

The study involved ten participants from Cavit ABI, eight male, and two female, with a mean age of 37.7 years (SD = 15.1). New Zealand European (N = 6) and Tongan (N = 1) ethnicities were represented in this sample, however it is possible that other ethnic groups were also represented as three participants chose not to specify.

Three of the participants had suffered stroke (mean age = 56), six had sustained closed brain injury (mean age = 29.2), and one had a brain tumour removed (age = 39). The mean number of days between the date of the injury and the date of initial assessment was 89.8 (SD = 38.9). Two participants indicated that they had sustained brain injuries prior to the occurrence of the current injury. According to DRS criteria, two participants had sustained a mild brain injury, three moderate, and five severe.

For the purpose of informed consent, each new client referred to Cavit ABI was provided with an information sheet (see Appendix 1) and a consent form (see Appendix 2). The client was asked if they would be interested in participating in the study and were given time to think about it and talk to family. Some participants were incapable of giving consent themselves due to the extent of their injuries; in which case consent was sought from a relative or close friend (see Appendix 3).

In the information sheet potential participants were asked that their personal rehabilitation progress be measured by staff at Cavit ABI, using six different outcome measures. They were advised that any personal information collected (e.g. age, gender, ethnicity) would only be used collectively to depict the characteristics of the general participant population. They were also made aware that declining to take part in this study would not affect their rehabilitation programme in any way and that they were free to withdraw their participation from the study at any stage. It was also stipulated that potential participants could contact the researcher if they had any questions regarding the study.

Those who agreed to participate in the study, or family who consented to their participation were asked to sign a consent form. The Massey University Human Ethics Committee (WGTN) has evaluated and approved this study (Protocol 03/151) and this method of obtaining informed consent is in accordance with the Massey University Code of Ethics.

Design

The proposed study used within-groups, non-experimental, pre-test, post-test design. Six outcome measure assessments were administered to 10 participants by trained Cavit ABI therapists (occupational therapists, physiotherapists, and speech-language therapists), using either interviewing or observation techniques. The assessments were undertaken on client admission to Cavit ABI, and again six weeks later. Additional to the six outcome measures, staff questionnaires were distributed to collect subjective data on the usefulness of each measure used. Of the eight questionnaires returned, five of those were completed by Occupational Therapists, one by a Speech-Language Therapist, and two did not specify.

For the present study, the independent variables are the outcome measures implemented in this study. The dependent variable is the degree to which each outcome measure assesses the level of functioning in a manner that can assist with the identification of specific rehabilitation goals. The level of functioning is defined by the criteria listed in Table 6.1. This criterion has been developed after reviewing the most common areas of functioning addressed by current outcome measures.

Table 6.1

Level of Functioning Criteria

Level of Functioning Criteria
Personal Care
Mobility
Physical Independence
Communication
Social Interaction & Participation In Recreational Activities
Family Contact
Emotional Functioning & Adjustment
Cognitive Functioning
Productive Activity
Financial Independence
Transportation

Additionally, competency criteria for the outcome measures were developed as a way of comparing each measure to a set of criteria that would make for the most ideal outcome measure in this particular rehabilitation setting. These criteria were developed after talking with the service manager and staff at Cavit ABI. The resulting eight criteria items, as listed in Table 6.2 below, are those indicated by staff to be the areas most important for an outcome measure to fulfil.

Table 6.2

Outcome Measure Competency Criteria

Outcome Measure Competency Criteria

1. The measure is absent of ceiling and floor effects
2. The criteria used for scoring is quick and simple to follow, with useful concluding interpretations.
3. The measure collects information that identifies rehabilitation goals specific to the needs of the individual/family.
4. There is space for the inclusion of input from the client and the relatives/close friends of the client.
5. The length of the administration of the measure is unlikely to cause fatigue.
6. The measure is capable of measuring change in functioning over time.
7. The measure is written in a manner that allows it to be understood by individuals with cognitive impairments.
8. The measure covers all or most of the domains of functioning (as described above in Table 6.1).

Administration of the six outcome measures was counter-balanced using randomly assigned sequences in order to control for the effects of staff fatigue.

The raw data scores for each of the six measures was recorded and analysed using a non-parametric Wilcoxon signed ranked test to determine the statistical significance of any change in score at outset and after rehabilitation. Furthermore, the mean rankings allocated by data collected from the staff questionnaire was analysed using a non-parametric Friedman test.

Measures

At the culmination of the review presented in Chapter Four, six outcome measures were selected to be included in the present study, by the service manager of Cavit ABI, Wellington, and the researcher. They were as follows: The Functional Independence Measure + Functional Assessment Measure (FIM + FAM), the Community Integration

Questionnaire (CIQ), the Disability Rating Scale (DRS), the Mayo-Portland Adaptability Inventory (MPAI-4), the Revised Craig Handicap Assessment and Reporting Technique (R-CHART), and the Brain Injury Community Rehabilitation Outcome Measures (BICRO-39). The latter five measures would be compared to the FIM + FAM (Appendix 5), the criterion outcome measure (in current use at Cavit ABI).

The DRS (Appendix 6) was included due to its focus on activity (disability) and because it is consistent with the model of rehabilitation and reportedly covers all of the areas of structure and function, activity, and participation, which are included in the model and are relevant to the purpose of this study (Zhang, et al., 2002). It also has the ability of measuring change over time and has favourable reports for reliability and validity. It allows rehabilitation staff to monitor progress in returning to previous life roles.

The CIQ has been selected due to its concentration on participation (Appendix 7). The inclusion of attention span, fatigability and memory problems as items to be assessed, make it a promising tool for using in a brain injury rehabilitation setting. The R-CHART was also incorporated for its focus on the participation area of rehabilitation (Appendix 8). This measure has also been widely used in outcome measures studies (Zhang, et al., 2002; Hall, Bushnik, Lakisic-Kazazic, Wright & Cantagallo, 2001; Cardol, Brandsma, de Groot, van der Bos, de Haans, & de Jong, 1999). Its ability to measure change in an individual and its concentration on objective criteria makes it a likely candidate for continued use at Cavit ABI.

Both the MPAI-4 and the BICRO-39 were included in the study, as they have been designed specifically for use within settings of brain injury. The MPAI-4 covers all structure/function, activity, and participation areas of the rehabilitation model (Appendix 9). The flexibility in terms of who completes the rating of the measure is also a very useful element as often clients at Cavit ABI are unable to write or speak at the level required to complete the questions.

The BICRO-39 has a number of favourable aspects that justify its inclusion in this study (Appendix 10). Firstly, its focus is on activity and participation areas of the rehabilitation model. Secondly, it is one of the few measures that contain a pre-injury and a post-injury rating form. This allows points of comparison to be made, which is particularly valuable considering staff generally have very little knowledge of a clients previous level of functioning before a brain injury has been sustained. There are also rating forms for carers to complete, thus giving family members the opportunity to provide feedback regarding the rehabilitation progress.

Points four and eight of Table 6.2 were easy areas to address before the six outcome measures were implemented in the study. Point four concerns the provision within an outcome measure for family members to make comment about the rehabilitation progress. The individuals, who are permitted to complete the rating forms, and the scoring trend for determining lower levels of functioning within each outcome measure, are presented in the table below.

Table 6.3

Scoring Trends, and Individuals Permitted to Complete Each Measure.

Measure	**Lower Functioning =**	**Completed By**
FIM+FAM	lower score	Therapist
BICRO-39	higher score	Patient/carer/therapist
MPAI-4	higher score	Patient/carer/therapist
CIQ	lower score	Patient/carer
DRS	higher score	Therapist
R-CHART	lower score	Therapist/patient

In terms of point 4, a carer or family member may rate the BICRO-39, MPAI-4 and CIQ. Of these, the BICRO-39 is the only outcome measure that provides an additional rating form specifically for this purpose.

Point eight required that an outcome measure be able to cover all or most of the domains of functioning specified in Table 6.1. Figure 6.1 below addresses this. This graph shows the number of domains of functioning that each outcome measure contains. This information was identified after looking at the subscales and individual items included in each outcome measure.

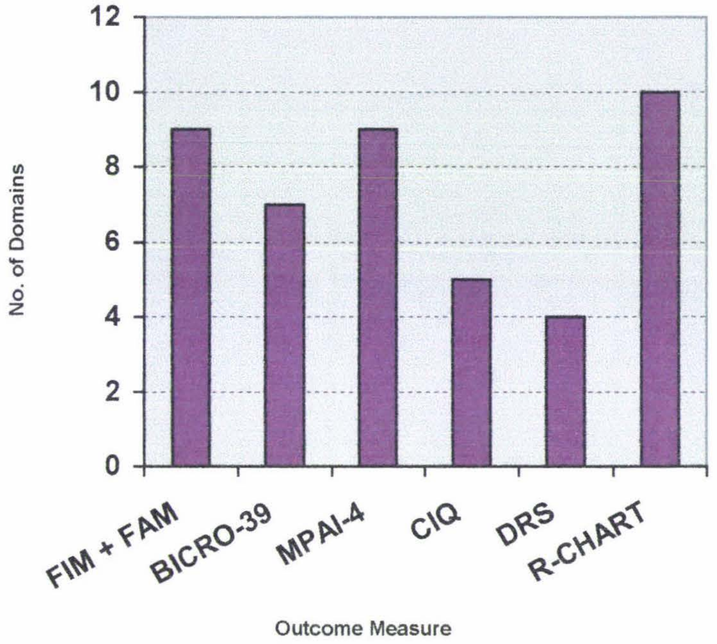

Figure 6.1: Number of Domains of Functioning Covered By Each outcome Measure.

The R-CHART is shown as the outcome measure that includes the most areas of functioning, with items covering 10 out of 11 domains. The MPAI-4 and the FIM + FAM also covered a large number of domains, each including items on nine specified areas of functioning. Tables 7.6 and 7.8 (in Chapter 7) provide information regarding the actual areas covered by the outcome measures.

Additional to the six outcome measures used in this study is a 'level of fatigue' scale that was to be completed at the end of each measure for each participant. This is a 5-point

Likert scale that staff can rate the degree which the measure would produce fatigue in an inpatient (see Appendix 11).

A staff questionnaire has also been developed that is to be distributed and completed by staff at the end of data collection (Appendix 12). This questionnaire has 5 items that collect information regarding the staff opinions on the usefulness of each measure. For example, one item used was "How easy is it for inpatients to understand the wording of the questions used in these measures?"

Procedure

Pre-study.

The six outcome measures used in the study were to be administered to participants by the specialist therapists working at Cavit ABI. Therefore training sessions on the outcome measures were required to establish interrater reliability before the study commenced. The researcher and the Wellington service manager ran workshops at both Auckland and Wellington centres. These sessions involved scoring all six measures using the same case example. Scores were then compared across the group, and any differences in scores were consequently discussed. The workshops also involved going over the key points of the scoring manuals for each outcome measure, which may have produced the scoring differences. If the manuals failed to make sufficient comment on specific protocols harbouring score differences, alternative scoring standards were established throughout Cavit ABI to increase the standardization of procedures for this study.

The Study.

Upon the admission of each new inpatient at Cavit ABI, the inpatient (and/or inpatients family) was approached by their key worker and asked if they would be interested in participating in this study. The inpatient was given at least two days to read over the information and decide whether they were willing to participate. Participants who agreed to take part were then administered the six randomly assigned outcome measures over several days during the first week of admission. It should be acknowledged that the BICRO-39, CIQ and R-CHART have been designed to be used within a community rather than an inpatient setting. However, for the objectives of this study and the available population sample, these measures will be used in an inpatient setting. The measures were then randomly administered again over several days following the sixth week of rehabilitation.

At this point, the therapist who had administered the measures completed a staff questionnaire, rating the six measures on appropriateness and usefulness for rehabilitation. All of the study resources were then sent to the researcher for analysis and statistical examination.

Chapter 7:
Results

Staff Questionnaire Ratings

Hypothesis 1: That staff will rate the MPAI-4 as significantly better at identifying specific rehabilitation goals (relative to the needs of the individual).

This hypothesis was tested using a Friedman non-parametric test. As predicted, the MPAI-4 was rated better by staff at identifying rehabilitation goals. The mean rank of the MPAI-4 was 1.71. The difference between measures was found to be significant χ^2 (5, N = 7) = 24.71, p < .001.

Table 7.1

Mean Ranks of Outcome Measures For Identifying Rehabilitation Goals.

Measure	Mean Rank
MPAI-4	1.71
FIM + FAM	2.14
BICRO-39	2.43
CIQ	4.57
DRS	4.86
R-CHART	5.29

Hypothesis 2: That staff will rate the DRS as significantly quicker and easier to administer (not including the FIM + FAM as it has already been identified as difficult to administer).

Although the DRS was overall rated by staff to be easier to administer and score than the other five outcome measures, with a ranking of 2.29, this difference was not statistically significant, χ^2 (4, N = 7) = 8.11, p > .05. Therefore, this hypothesis was not supported.

Table 7.2

Mean Ranks of Outcome Measures For Administration Simplicity.

Measure	Mean Rank
DRS	2.29
CIQ	2.43
BICRO-39	2.86
MPAI-4	3.00
R-CHART	4.43

Hypothesis 3: That staff will rate the BICRO-39 as easier for clients to understand in terms of layout and wording than other client self-rating forms (the FIM + FAM and the DRS are not included here as they can only be completed by staff members).

Using the Friedman non-parametric test, this hypothesis was supported. The BICRO-39 was rated as the easiest measure to understand. The difference between measures was statistically significant, χ^2 (5, N = 7) = 11.43, p < .05.

Table 7.3

Mean Ranks of Outcome Measures For User-friendliness.

Measure	Mean Rank
BICRO-39	1.86
CIQ	2.79
MPAI-4	3.43
R-CHART	4.21

Hypothesis 4: The DRS will be rated as producing significantly less fatigue for staff.

This hypothesis was correct. Figure 7.1 below shows that only two staff (out of a possible nine) rated the DRS as producing any level of fatigue.

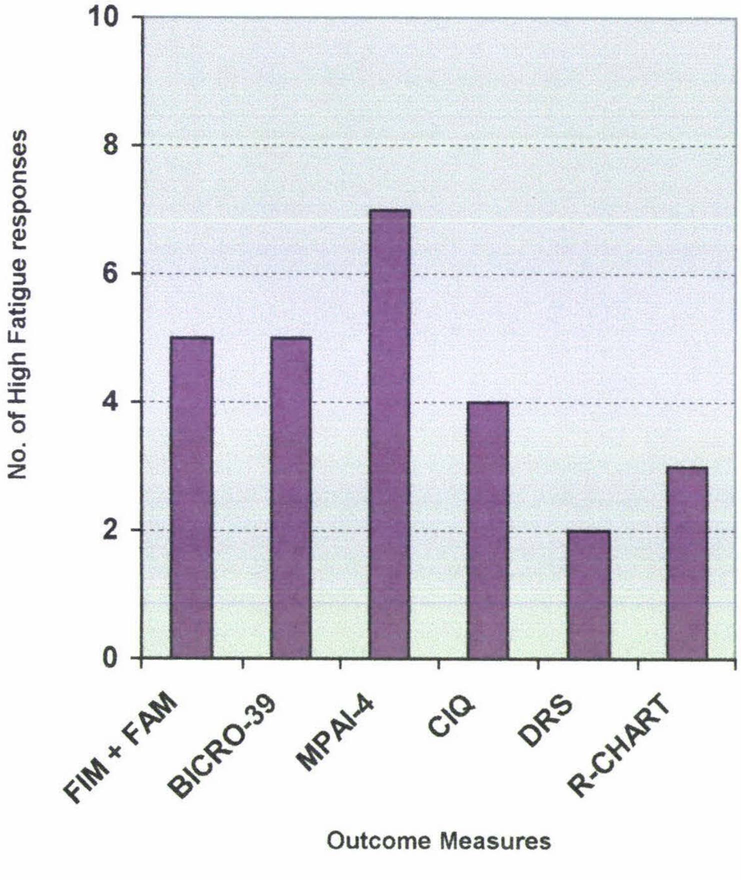

Figure 7.1. Staff Ratings For Level of Fatigue.

Hypothesis 5: Staff will choose the MPAI-4 as a preferred measure.

Five of the seven therapists chose the MPAI-4 as a measure to continue using. This can be seen in Table 7.4 below which shows the number of times each outcome measure was selected by staff. However, as Table 7.4 indicates, all seven therapists indicated that they would prefer to continue using the FIM + FAM. Therefore, the MPAI-4 was not the most preferred measure chosen.

Table 7.4

Frequency of Outcome Measures Chosen For Continued Use.

Measure	Number of Times Chosen
FIM + FAM	7
MPAI-4	5
BICRO-39	2
CIQ	0
DRS	0
R-CHART	0

Subjective data was collected from staff members concerning favourable and non-favourable aspects of each outcome measure. The following are common statements made about the outcome measures.

FIM + FAM: Positive:

"Clear guidelines"

"Shows Rehabilitation Progress."

Negative:

"Contains ceiling effects…person can still have functional issues yet score highly…..does not highlight specific goals"

"Takes more time than the other outcome measures."

BICRO-39: Positive:

"Clear summary to relate to goals, well set out to allow for visual limitation"

"Good that it incorporates client and caregiver."

Negative:

"No differentiation between don't do at all because of lack of ability, or just not part of daily life"

"Would be better suited to use with someone in the community."

MPAI-4: Positive:

"Covers a lot of specific items for head injury"

"Very comprehensive and workable with interdisciplinary team."

Negative:

"Too long"

"Difficult to score."

CIQ: Positive:

"Good for pre-discharge"

"Quick and easy to administer."

Negative:

"Doesn't take into account why people don't do activities"

"Not relevant to inpatient setting."

DRS: Positive:

"Quick and easy to administer"

"Good if clients severely impaired."

Negative:

"Too limiting for higher functioning clients"

"Not relatable to cognitive improvement on recovery."

R-CHART: Positive:

"Easy to see where changes have occurred"

"Good overview of performance in community."

Negative:

"Some questions are inappropriate"

"Difficult to score."

Measured Abilities

Hypothesis 6: That the FIM + FAM will be significantly more sensitive at detecting change in functioning over time, than all other outcome measures tested.

Table 7.5 provides the Z scores and actual significance scores generated using a Wilcoxon signed rank test to analyse the degree to which each outcome measure is sensitive to change. As the table shows, four of the six measures showed a significant level of change between admission and six week assessments. However, the FIM + FAM was the most sensitive to change ($z = -2.803$, $p < .01$), therefore hypothesis 6 is supported.

Table 7.5

Ability to Measure Change in Functioning As Shown By Significance Scores Generated By a Wilcoxon Signed Rank Test.

Measure	**Differences**	
	Z	*p*
FIM + FAM	-2.803	.005*
R-CHART	-2.380	.017**
DRS	-2.375	.018**
MPAI-4	-2.103	.035**
BICRO-39	-.652	.515
CIQ	.000	1.000

*Statistically significant at < .01 level

**Statistically significant at < .05 level

Significant improvements to cognitive functioning were indicated by three of the outcome measures (DRS, FIM + FAM, and the R-CHART), as shown by Table 7.6 below. This is the most common domain of functioning to show significant change. None of the outcome measures incorporating social integration and participation domains showed significant levels of change.

Table 7.6:
Change in Functioning Between Time 1 & Time 2 on domains of function within outcome measures

	Time 1	**Time 2**
BICRO-39		
Personal Care	1.604	.109
Mobility	1.104	.310
Self Organisation	0.000	1.000
Contact with Partner/children	.674	.500
Contact with Parents/siblings	.333	.739
Socialising	.140	.888
Productive Employment	1.069	.285
Psychological Well-being	1.334	.184
CIQ		
Home Integration	0.000	1.000
Social Integration	0.000	1.000
Productivity Score	.544	.586
DRS		
Arousal, Awareness	2.333	.020*
Cognitive Ability	2.226	.026*
Dependence on Others	1.289	197
Psychosocial Adaptability	1.000	.317
FIM + FAM		
Self Care	1.063	.288
Sphincter Control	1.633	.102
Mobility	1.604	.109
Locomotion	1.826	.068
Communication	2.521	.012*
Psychosocial Adjustment	2.328	.020*
Cognitive Function	2.668	.008**
MPAI-4		
Abilities	2.558	.011*
Adjustment	1.192	.233
Participation	1.612	.107
R-CHART		
Physical Independence	.943	.345
Cognitive Independence	2.240	.035*
Mobility	2.380	.017*
Occupation	0.000	1.000
Social Integration	.840	.401

*Statistically significant at < .01 level

**Statistically significant at < .05 level

Hypothesis 7: Clients with mild to moderate brain injuries will show more change between time 1 and time 2 on the MPAI-4 than other measures.

Hypothesis 8: Clients with severe brain injuries will show more change between time 1 and time 2 on the BICRO-39 than other measures.

Table 7.7

Change in Functioning Between Time 1 and Time 2 on all Outcome Measures for Mild-Moderate and Severe Groups.

Measure	**Severity**			
	Mild – Moderate *(N = 5)*		*Severe* *(N = 5)*	
	Z	p	Z	p
DRS	2.032	.042*	1.414	.157
FIM + FAM	2.023	.043*	2.023	.043*
MPAI-4	1.461	.144	1.841	.066
R-CHART	1.069	.285	2.023	.043*
CIQ	.539	.539	.816	.414
BICRO-39	.365	.751	.674	.500

*Statistically significant at < .05 level

Table 7.7 above shows that neither hypothesis was supported. The FIM + FAM and DRS showed statistically significant change in functioning over time for participants with mild-moderate brain injuries. Both measures indicated improvement of function as a result of time in rehabilitation. The FIM + FAM and R-CHART showed statistically significant change in functioning over time for participants with severe brain injuries. Both measures also indicated improvement of function as a result of time in rehabilitation.

Hypothesis 9: All outcome measures will have ceiling and/or floor effects.

Table 7.8 presents the percentage of the participants in this study who scored the highest and lowest possible scores on each outcome measure. Many of the outcome measures subscales show large percentages of participants reaching the ceiling and floor boundaries. While the FIM + FAM, MPAI-4, and R-CHART report no ceiling or floor effects for total score, the MPAI-4 in its entirety did not present with any participants reaching the highest or lowest scores. Therefore, this hypothesis is not supported.

Table 7.8

Percentage of Participants Who Reached the Ceiling and/or Floor Boundaries of Each Outcome Measure, For Time 1 and Time 2.

Measure	**Ceiling Effect** (%)		**Floor Effect** (%)	
BICRO-39	**Time 1**	**Time 2**	**Time 1**	**Time 2**
Personal Care	4	67	0	0
Mobility	22	22	56	11
Self Organisation	11	11	33	22
Contact with Parter/children	11	0	33	44
Contact with Parents/siblings	22	0	22	11
Socialising	11	0	33	11
Productive Employment	11	0	78	78
Psychological Well-being	11	0	0	0
Total Score	10	0	0	0
CIQ				
Home Integration	0	0	20	20
Social Integration	0	0	10	0
Productivity Score	10	0	30	20
Total Score	0	0	10	0
DRS				
Arousal, Awareness	30	80	0	0
Cognitive Ability	30	60	0	0
Dependence on Others	20	30	10	0
Psychosocial Adaptability	10	20	70	60
Total Score	10	10	0	0
FIM + FAM				
Self Care	20	0	0	0
Sphincter Control	60	70	0	0
Mobility	60	70	10	0
Locomotion	30	30	30	10
Communication	0	20	0	0
Psychosocial Adjustment	0	0	0	0
Cognitive Functioning	0	0	10	0
Total Score	0	0	0	0
MPAI-4				
Abilities	0	0	0	0
Adjustment	0	0	0	0
Participation	0	0	0	0
Total Score	0	0	0	0
R-CHART				
Physical Independence	10	10	0	0
Cognitive Independence	0	10	10	0
Mobility	0	10	0	0
Occupation	20	0	40	10
Social Integration	10	10	0	0
Total Score	0	0	0	0

Chapter 8

Discussion

The purpose of the present study was to identify one or more outcome measures suitable for use in a rehabilitation setting. In that they were successful at indicating levels of activity limitations and participation restrictions for individuals with brain injuries. It was hoped that a method for outcome measurement would be revealed that was an improvement on the FIM + FAM. It was also proposed that different outcome measures could be identified as being useful for varying degrees of severity.

All of the outcome measures implemented show some degree of improvement in participants over the six-week period, thus it may be concluded that progress in rehabilitation was successful. However, none of the outcome measures were without limitations. For instance, only the FIM + FAM was able to show significant change on a subscale of social integration and/or participation in recreational activities. These subscales are especially important for determining the activity limitations and participation restrictions that an individual may be experiencing.

There are three main reasons why this may have occurred. Firstly, the outcome measures may contain inadequate items for measuring limitations to functioning in these areas. Secondly, it may have been that a six-week time frame was too short to identify significant changes in areas of social integration and participation in recreational activities. Finally, it may be that not enough emphasis is placed on fulfilling rehabilitation goals related to these areas in an inpatient setting. The findings regarding further strengths and weaknesses of each of the six outcome measures involved, is presented below. This is followed by a discussion of the conclusions drawn from the findings, the limitations of the present study, and suggested areas for further research.

BICRO-39

This measure did not prove to be as useful or favourable among staff as initially predicted. The BICRO-39 only covered seven of the eleven ideal domains of functioning, failing to include items related to physical independence, communication ability, emotional functioning, cognitive functioning, transportation accessibility and participation in recreational activities. Of the domains it does cover, ceiling effects were evident for a high percentage of participants for the personal care subscale (67%), while floor effects were present for mobility (56%), and socialising (78%). A reasonable level of fatigue is also produced by this outcome measure, with a total of 39 items.

The BICRO-39 was found to produce a non-significant change in functioning over time. Furthermore, it received only the median rankings for its ability to collect information outlining specific rehabilitation needs and for its ease of administration. The BICRO-39 was rated by staff as the easiest measure to understand, and it provides opportunity to include input from others and attempts to measure pre-injury levels of functioning, still only two staff members selected this measure as one they would like to continue using.

CIQ

Only five of eleven domains of functioning were covered by the CIQ and a small percentage of participants (10% - 30%) were affected by ceiling and floor affects on some subscales. It did not identify specific goals of rehabilitation nor provide room for input from others significant to the clients. Its ability to measure change was also not significant. Staff rated the CIQ in the top three for ease of understanding, and scoring and interpreting information collected, however no one selected this measure for further use at Cavit ABI.

DRS

Of the eleven specified domains of functioning, the DRS covered four, thus making it a highly impractical instrument for further implementation in this setting. Three of the four subscales produced a large rate of ceiling and floor effects (60% - 80%). This measure also lacks the ability to identify specific goals, ranked in the bottom three by staff; or provide input from significant others. Staff also ranked the DRS in the bottom three for its capacity (or lack of) to be easily understood by scorers.

As predicted, staff did rate the DRS as being easy to score and interpret, and as producing the least fatigue. It was also able to measure change in functioning at a significant level. As the DRS only covers four domains of functioning and produced high levels of ceiling and floor effects, this measure would not be of any real use to this particular rehabilitation setting. Nor was the DRS chosen by any staff member for further use.

R-CHART

This measure proved to be quite extensive in its inclusion of the specified domains of functioning, with only one of the domains not featured in the measure (emotional functioning and adjustment). The R-CHART was able to measure change in functioning at a significant level, and was rated by staff as producing a low level of fatigue.

Staff ranking, however, placed the R-CHART in the bottom three in terms of how easy questions were understood, and worst for identifying rehabilitation goals and being quick and easy to score and administer. A small degree of ceiling and floor effects were evident (10% - 40%) on some subscales and furthermore, it became apparent during data collection that some of the questions asked were inappropriate and difficult to determine. For example, all participants declined to answer the questions pertaining to economic self-sufficiency. Researchers in Australia have reported similar reservations (Ponsford, Olver, Nelms, Curran, & Ponsford, 1999). It is no surprise therefore that the R-CHART was not chosen by any of the staff for possible continued use.

MPAI-4

The MPAI-4 contained nine of the eleven domains of functioning specified and allowed for input from others significant to the client. Only personal care and physical independence domains are not included. The results indicate that this instrument was able to measure a significant change in functioning between assessment periods. Also, the present study identified no ceiling or floor effects for this measure, contrary to other research findings (Malec, Moessner, Kragness, & Lezak, 2000).

As predicted, staff rated the MPAI-4 as best at identifying specific rehabilitation goals, and it was also rated within the top three for being easy to understand. It scored lower in terms of its ease of scoring and interpreting, and its level of induced fatigue. Regardless of these downfalls, it appears that many staff were willing to sacrifice time for quality of assessment, with five of seven staff members preferring to continue with this measure.

FIM + FAM

This measure was incorporated as the criterion against which the other five outcome measures could be compared. It covers nine of the eleven domains of functioning, which is one less than the R-CHART. Domains not covered included family contact, financial independence, and participation in recreational activities. Although it does not provide space for significant others to have input, the FIM + FAM proved to be more sensitive to change than any of the other measures used.

Staff comments and rankings indicated that the FIM + FAM is perceived to be a very long measure to rate; is difficult to understand; was identified to produce a reasonable level of fatigue, and considerable ceiling effects (20% - 70%) and floor effects (10% - 30%). This is in keeping with other research findings (Turner-Stokes, 1999; Hobart et al., 2001). However, staff ranked the measure as second to the MPAI-4 for its ability to identify specific goals. Surprisingly, all of the staff members indicated that they would prefer to continue using this measure. It is possible that this may be due to staff members current familiarity with the FIM + FAM, and possible resistance to change.

Conclusions

Using Different Measures to Suit the Severity of the Brain Injury.

The findings indicate that the FIM + FAM and the DRS were significantly sensitive to change for participants with mild to moderate brain injuries. For the group of participants with severe injuries, sensitivity to change was found to be significant by the FIM + FAM and the R-CHART. Given that each group contained only five inpatients, the reliability and validity of these results are negatively affected. Therefore it may be appropriate to not to make any specific conclusions regarding the ability of these outcome measures to assess individuals with brain injuries of differing severity.

Using Two or More Measures Together to Replace the FIM + FAM.

It is difficult to determine if using two or more measures to replace the FIM + FAM would be effective. Each of the five outcome measures have their own limitations and in terms of reliability and validity, it is unclear from the findings of the current study whether two measures would successfully fit together to assess different aspects of functioning for individuals with brain injuries.

Is There an Outcome Measure More Useful Than the FIM + FAM?

Each of the outcome measures included in this study contained their own unique strengths, but unfortunately, the findings indicate that none are able to fulfil all the desired requirements. In fact it is possible that such an outcome measure for brain injury rehabilitation does not yet exist.

From the findings, it appears that overall the FIM + FAM is still the outcome measure most wished for continued use. Although it is long and difficult to score, it seems that staff have become accustomed to this measure, ranking some elements rather favourably. The FIM + FAM also showed the most significant sensitivity to change. However, if this measure was to be retained, some major problems still exist. Firstly, this measure does not allow for significant others to comment on the level a family member is functioning at. Secondly, it does not include items covering financial independence and participation in recreational activities, which are key aspects required if participation restrictions are to be successfully identified.

Given these considerations the MPAI-4 appears to possess a number of aspects that make it a likely candidate for successful implementation in the current setting. For example, it was found to produce no ceiling or floor effects in the present participant sample. It also offers a versatile rating system that may be scored by staff members, significant others, or the client themselves ("Overview of the MPAI-4," 2003). There are two possible ways of utilising the MPAI-4. Firstly, on its own the MPAI-4 contains items that encompass participation in recreational activities, financial independence, and contact with family, making it ideal for measuring activity limitations and participation restrictions if this is the key area of focus.

However, its absence of items concerning personal care and physical independence mean that it does not adequately cover all domains of functioning, particularly those relating to structure and functioning of the body. In an inpatient rehabilitation setting, these items are of great importance as initial goals revolve around helping an inpatient to become physically self-sufficient. Therefore, a second possibility is to administer the

MPAI-4 alongside the FIM + FAM. This would allow all areas of functioning to be assessed for the individual.

While this solution sounds promising, two issues would still remain. Both the MPAI-4 and FIM + FAM are rather long outcome measures, containing 30 questions each, thus producing a total of 60 questions. Obviously this would be very time consuming. Secondly, there are a number of areas where these measures overlap with one another, resulting in little justification for using so much time to rate these measures. A possible solution to this situation, would be to consider using specific subscales from the FIM + FAM to cover the areas that the MPAI-4 does not contain. Although alternative, this may have a negative affect on the reliability and validity of both measures.

Limitations of the Study

Several limitations have affected the outcome of this study. Firstly, a number of issues are evident when considering the sample implemented in this study. The largest of which concerns sample size in that only ten participants were involved. This small number seriously reduces the validity and reliability of any of the studies findings. Furthermore, given the population that this research focuses on, differences in the severity and type of damage to the brain are inevitable. Thus the sample consists of a relatively uncontrolled population. Additionally, the sample is unrepresentative for gender as only two females were recruited for the study. This makes it difficult to relate the findings to a wider rehabilitation population.

Issues of reliability and validity were further aggravated by incomplete data sets. Some data returned to the researcher had not been completed as specified. This resulted in less than ten data sets being available for some areas of statistical analysis.

Results may also be influenced by the presence of possible confounds. Efforts were made to standardize the administration and scoring procedures for all six outcome measures, by providing training to staff prior to beginning data collection. However, it is possible that not all therapists had abided by the set methods of administration and scoring. This raises concern for the level of interrater reliability.

A further confounding factor arises from the research setting. Although both the Auckland and Wellington Cavit ABI centres function according to the same paradigm, some variances in service provision between the centres are likely to exist. Such differences affect standardization and therefore the reliability and validity of the results. Further, although Cavit ABI adheres to proven models of rehabilitation, the degree to which the current results generalise to other rehabilitation settings is speculative.

A limitation concerning a design factor also exists. The six-week time frame scheduled between the pre-test and post-test conditions is too short in most cases, to encompass the maximum change in functioning. Often inpatients remain in rehabilitation for several months before being discharged back into the community. Ideally, assessment would occur at admission to post-acute rehabilitation, and at discharge from the rehabilitation service.

Finally, the lack of existence of similar studies has meant that the findings of this study cannot be readily compared to the conclusions of other research.

Considerations For Future Research

A replication of this study incorporating a larger sample size and more sophisticated methods of statistical analysis is recommended. It would also be worthwhile conducting a study into the possibility of using the subscales from the FIM + FAM in conjunction with the MPAI-4. Particularly looking at the self-care, sphincter control, mobility and locomotion subscales, as these areas of physical independence are not covered by the MPAI-4.

It is strongly recommended that research be conducted into the development of a new outcome measure specifically for use in brain injury rehabilitation that incorporates a number of important elements. Firstly, a new measure would need to integrate the new international guidelines of the ICF model of rehabilitation, particularly with consideration to items consistent with the body structure and functioning, activity limitations, and participation restrictions outlined by the ICF. Ideally, a new measure would attempt to assess pre-morbid levels of functioning, allow input from significant others, cover all of the important domains of functioning, identify specific goals in relation to these domains of functioning, be sensitive to changes, and have a clear, concise method of collecting and interpreting information.

Furthermore, it would be interesting if research were conducted into the opinions that professionals from different occupations have of their role within the rehabilitation process. Many of the comments collected from therapists involved in this study gave the impression that reducing participation restrictions for clients was not as highly prioritised as other job roles. The idea supports the observation that it is not necessarily commonplace in brain injury rehabilitation settings to conduct follow-ups on client progress in the community once they have been discharged. Although, areas of activity limitation, and participation restrictions, are likely to become more obvious to an individual once they are in a community setting.

Summary

In conclusion, the findings suggest that while the FIM + FAM is a measure somewhat more useful than other available outcome measures examined in this study, the MPAI-4 is a measure which overcomes a number of the limitations of the FIM + FAM. Therefore the MPAI-4 is recommended for use at post-acute brain injury rehabilitation services such as Cavit ABI.

However, it must be noted that service providers need to be mindful of, and take into consideration, the limiting factors of the MPAI-4 when administering this instrument to clients. Furthermore, research should be considered that examines the possibility of using the physical independence subscales of the FIM + FAM along with the MPAI-4 to obtain a full understanding of the needs of the client. Perhaps more ideally, future research should focus on the development of a new comprehensive outcome measure that assesses activity limitations and participation restrictions in manner that is of most relevance to the post-acute brain injury rehabilitation setting.

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Appendices Page

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Outcome Measures In Brain Injury Rehabilitation

Information sheet

My name is Christina Robinson. I am a postgraduate student at Massey University. I am currently conducting a study along side staff at Cavit ABI, in order to complete a Master's thesis in psychology. I can be contacted on (027) 4049 049, or via email at steinyr@actrix.co.nz. The supervisor for this study is Professor, Janet Leathem, who may be contacted at the Massey University Wellington Campus, on (04) 801 2794 ext 6768.

As part of your rehabilitation programme, during your time at Cavit ABI, information is collected on the outcome of your rehabilitation. This is to identify progress while you are receiving input from the rehabilitation staff.

We are conducting a research project directed at finding out what is the best measurement of progress in brain injury rehabilitation. And would like to include you in the study. We hope to gather information from around 50 people so that we can see which measurement gives the best indication of rehabilitation progress.

Agreeing to take part would mean that the staff at Cavit ABI would complete six rehabilitation assessments. Information would also be collected about age, gender, and ethnicity. The information used in this study will not identify you by name and will be stored in secure files at Cavit ABI.

It is your choice to have your information included or not in this study. If you do not wish it to be included, this will not affect the rehabilitation that you receive. You have the right to withdraw your information at any time.

There are no known side effects or possible risks involved with participating in this study.

If at any stage you would like more information regarding this study, please contact my supervisor Janet Leathem or myself, using the contact details provided.

If you wish, a summary of the results of this study can be sent to you after the study's completion.

The Massey University Human Ethics Committee, WGTN Protocol NO/NO, and the National Human Ethics Committee have reviewed and approved this study. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Campus Human Ethics Committee: Wellington, telephone 04 801 2794 ex6723, email J.J.Hubbard@massey.ac.nz .

Thank you
Christina Robinson

January 2004

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Outcome Measures In Brain Injury Rehabilitation

Consent Form

This consent form will be held for a period of 5 years

I have read this Information Sheet and have had the details of the study explained to me. All my questions regarding this study have been answered. I understand that I may ask further questions at any time. I also understand that the rehabilitation I receive will not be affected if I do not wish to have my information included in this study.

(Please circle the most appropriate answer below)
I wish/do not wish to be provided with a summary of the results of this study when they are available.

I do agree/ I do not agree to the inclusion of my information in this study, under the conditions set out in the Information Sheet.

Signature: **Date:**

Full name (printed):

Address for study results to be sent to:

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Outcome Measures In Brain Injury Rehabilitation
Statement By Relative/Friend/Whanau

Principle Investigator: Christina Robinson

Participant's Name: ______________________

I have read and I understand the information sheet dated January 2004 for people taking part in the study designed to identify the best measures of progress in brain injury rehabilitation. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I believe that ________________________ (participant's name) would have chosen and consented to participate in this study if he/she had been able to understand the information that I have received and understood.

I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if he/she wishes. This will not affect his/her continuing rehabilitation.

I understand that his/her participation in this study is confidential and that no material, which could identify him/her will be used in any reports on this study.

I understand that the collection of information will be stopped if it should appear to be distressful to the participant.

I know whom to contact if anything occurs which I think my relative/friend would consider a reason to withdraw from the study.

This study has been given ethical approval by the Massey University Human Ethics Committee. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

I/my relative friend would like a copy of the results of the study **YES/NO**

Outcome Measures In Brain Injury Rehabilitation

I believe my relative/friend would agree to his/her GP being informed of his/her participation in this study

YES/NO

Signed: **Date:**

Printed Name:

Relationship to Participant:

Address for Results to be Sent:

Statement by Principle Investigator

I Christina Robinson declare that this study is in the potential rehabilitation interest's of the group of patients of which ______________________ is a member and that participation in this study is not adverse to ____________________ interests.

Signed: Date:

Statement By Independent Clinician

I confirm that participation in the study is not adverse to this participant's interests.

Signed: **Date:**

Printed Name:

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Outcome Measures In Brain Injury Rehabilitation

Dear therapist,

In this envelope please find enclosed: an inpatient information sheet, two different consent forms, a form for the inpatients personal details, and two bundles containing the six outcome measures that are to be completed.

If necessary, each new inpatient or the inpatients family should be given at least two days to think about consenting to participation in this study. Once the inpatient/inpatient's family have read and signed the information sheet and consent forms, these forms need to be collected and placed back into the envelope. Once consent has been granted, the six measures **must be** completed before the end of the week of admission, in the order that they have been stapled together. Except for the FIM+FAM, which should be scored by a combination of therapists, the key worker must complete the other five measures. All measures may be completed over a **two-day period**.

The specific instructions for each measure need to be followed carefully and manuals must be used where applicable. Standardized assessment procedures increase the validity of the study. For instance, a decision tree must be utilised when rating the FIM+FAM and manuals must be referred to when rating the MPAI-4 and the CHART. There is also scoring syllabus available for the CIQ and the DRS, which should be used as a rating guide. If you have any queries regarding the BICRO-39, please contact either myself, or Kieran Hobbs.

If, in order to complete a measure, you need to enquire about any information, you may use any of the measures as a standardized interview with the participant.

You will find that across the top, the stapled bundles have been labelled with either 'Admission' or 'Six Weeks'. Please use the appropriate bundle for each assessment. The 'level of fatigue' scales must be completed at the end of each outcome measure. Please remember to date each individual outcome measure and record the assigned participant number. This number is located on the front of the envelope provided.

Completed bundles should be returned to the appropriate envelope, ready to be collected by myself for analysis. Please store this envelope and it's contents, at the back of the inpatients file.

If you have any questions regarding any aspect of this study, you can contact me via email at steinyr@actrix.co.nz, or on 027 4049 049.

I would like to thank you for your participation in this study. It is hoped that the results of this study will help to identify an outcome measure that assists Cavit ABI in continuing to provide its specialised rehabilitation service in the future.

Regards,
Christina Robinson

APPENDIX 5

FIM + FAM Rating Form

FUNCTIONAL INDEPENDENCE MEASURE^{TM} AND FUNCTIONAL ASSESSMENT MEASUR
Brain Injury

Scale:
7 Complete Independence (timely, safely)
6 Modified Independence (extra time, devices)
5 Supervision (cuing, coaxing, prompting)
4 Minimal Assist (performs 75% or more of task)
3 Moderate Assist (performs 50%-74% of task)
2 Maximal Assist (performs 25% to 49% of task)
1 Total Assist (performs less than 25% of task)

(Patient Stamp)

SELF CARE ITEMS	Adm	Goal	D/C	F/U
1. Feeding				
2. Grooming				
3. Bathing				
4. Dressing Upper Body				
5. Dressing Lower Body				
6. Toileting				
7. Swallowing*				

SPHINCTER CONTROL				
8. Bladder Management				
9. Bowel Management				

MOBILITY ITEMS (Type of Transfer)				
10. Bed, Chair, Wheelchair ____________				
11. Toilet ____________				
12. Tub or Shower ____________				
13. Car Transfer* ____________				

LOCOMOTION				
14. Walking/Wheelchair (circle)				
15. Stairs				
16. Community Access*				

COMMUNICATION ITEMS				
17. Comprehension-Audio/Visual (circle)				
18. Expression-Verbal, Non-Verbal (circle)				
19. Reading*				
20. Writing*				
21. Speech Intelligibility*				

PSYCHOSOCIAL ADJUSTMENT				
22. Social Interaction				
23. Emotional Status*				
24. Adjustment to Limitations*				
25. Employability*				

COGNITIVE FUNCTION				
26. Problem Solving				
27. Memory				
28. Orientation*				
29. Attention*				
30. Safety Judgement*				

*FAM items

	Admt	Date	D/C	Date		Admt	Date	D/C	Date
RN	______	______	______	______	ST	______	______	______	______
PT	______	______	______	______	PSY	______	______	______	______
OT	______	______	______	______	REC	______	______	______	______

APPENDIX 6

DRS Rating Form

Patient Name______________________________
Rater______________________________
Date Completed______________________________

Disability Rating Scale (DRS)

Arousability, Awareness, & Responsivity

Eye Opening
☐ 0 Spontaneous
☐ 1 To Speech
☐ 2 To Pain
☐ 3 None

Communication Ability
☐ 0 Oriented
☐ 1 Confused
☐ 2 Inappropriate
☐ 3 Incomprehensible
☐ 4 None

Motor Response
☐ 0 Obeying
☐ 1 Localizing
☐ 2 Withdrawing
☐ 3 Flexing
☐ 4 Extending
☐ 5 None

Cognitive Ability for Self Care Activities

Knows how and when to feed, toilet or groom self

Feeding
☐ 0.0 Complete
☐ 0.5
☐ 1.0 Partial
☐ 1.5
☐ 2.0 Minimal
☐ 2.5
☐ 3.0 None

Toileting
☐ 0.0 Complete
☐ 0.5
☐ 1.0 Partial
☐ 1.5
☐ 2.0 Minimal
☐ 2.5
☐ 3.0 None

Grooming
☐ 0.0 Complete
☐ 0.5
☐ 1.0 Partial
☐ 1.5
☐ 2.0 Minimal
☐ 2.5
☐ 3.0 None

Dependence on Others

Level of Functioning
Physical & cognitive disability

☐ 0.0 Completely Independent
☐ 0.5
☐ 1.0 Independent in special environment
☐ 1.5
☐ 2.0 Mildly Dependent-Limited assistance *Non-resident helper*
☐ 2.5
☐ 3.0 Moderately Dependent-moderate assist *Person in home*
☐ 3.5
☐ 4.0 Markedly Dependent *Assistance with all major activities, all times*
☐ 4.5
☐ 5.0 Totally Dependent *24 hour nursing care*

Psychosocial Adaptability

Employability
As full time worker, homemaker, student

☐ 0.0 Not Restricted
☐ 0.5
☐ 1.0 Selected jobs, competitive
☐ 1.5
☐ 2.0 Sheltered workshop, Noncompet.
☐ 2.5
☐ 3.0 Not Employable

Total Score (sum all scores) _______

Revised 2/99 Santa Clara Valley Medical Center

APPENDIX 7

CIQ Rating Form

COMMUNITY INTEGRATION QUESTIONNAIRE

Subject: ______________________________ **Date:** ________________

1. Who usually does the shopping for groceries or other necessities in your household?	○ Yourself alone ○ Yourself and someone else ○ Someone else
2. Who usually prepares meals in your household?	○ Yourself alone ○ Yourself and someone else ○ Someone else
3. In your home who usually does the everyday housework?	○ Yourself alone ○ Yourself and someone else ○ Someone else
4. Who usually cares for the children in your home?	○ Yourself alone ○ Yourself and someone else ○ Someone else ○ Not applicable, No children under 17 in the home
5. Who usually plans social arrangements such as get-togethers with family and friends?	○ Yourself alone ○ Yourself and someone else ○ Someone else
6. Who usually looks after your personal finances, such as banking or paying bills?	○ Yourself alone ○ Yourself and someone else ○ Someone else
7. Approximately how many times a month do you usually participate in shopping *outside* your home?	○ Never ○ 1 - 4 times ○ 5 or more
8. Approximately how many times a month do you usually participate in leisure activities such as movies, sports, restaurants, etc.	○ Never ○ 1 - 4 times ○ 5 or more
9. Approximately how many times a month do you usually visit your friends or relatives?	○ Never ○ 1 - 4 times ○ 5 or more
10. When you participate in leisure activities do you usually do this alone or with others?	○ Mostly alone ○ Mostly with friends who have head injuries ○ Mostly with family members ○ Mostly with friends who do not have head injuries ○ With a combination of family and friends

Please complete page two

COMMUNITY INTEGRATION QUESTIONNAIRE (Page 2)

11. Do you have a best friend with whom you confide?	○ Yes ○ No
12. How often do you travel outside the home?	○ Almost every day ○ Almost every week ○ Seldom/never (less than once per week)
13. Please choose the answer that best corresponds to your current (during the past month) work situation:	○ Full-time (more than 20 hours/week) ○ Part-time (less than or equal to 20 hrs/week) ○ Not working, but actively looking for work ○ Not working, not looking for work ○ Not applicable, retired due to age
14. Please choose the answer that best corresponds to your current (during the past month) school or training program situation:	○ Full-time ○ Part-time ○ Not attending school, or training program ○ Not applicable, retired due to age
15. In the past month, how often did you engage in volunteer activities?	○ Never ○ 1 - 4 times ○ 5 or more

Comments:

APPENDIX 8

R-CHART Rating Form

Revised Craig Handicap Assessment and Reporting Technique Scoring Form

1. How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?

______ hours paid assistance ______ hours unpaid (family, others)

2. Not including any regular care as reported above, how many hours in a <u>typical month</u> do you occasionally have assistance with such things as grocery shopping, laundry, housekeeping, or infrequent medical needs because of the disability?

________ hours per month

3. Who takes responsibility for instructing and directing your attendants and/or caregivers?

_____ Self
_____ Someone Else
_____ Not applicable, does not use attendant care

		PHYSICAL INDEPENDENCE
A.	Total the hours of paid and unpaid care.	________ +
B.	Divide the hours of occasional care by 30.	(______ / 30) =
C.	Add the sums of "A" and "B".	________
D.	If the respondent instructs and directs his/her own attendants or caregivers, multiply the answer of "C" by 3. If someone other than the respondent instructs and directs the attendants or care givers, multiply the answer of "C" by 4.	X 3 or 4 = ________
E.	Subtract the total in "D" from 100.	100 minus ________ sum from "D" above = ☐

COGNITIVE
INDEPENDENCE

4. How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgment?

1______ Someone else is always with me to observe or supervise.
2______ Someone else is always around, but they only check on me now and then.
3______ Sometimes I am left alone for an hour or two.
4______ Sometimes I am left alone for most of the day
5______ I have been left alone all day and all night, but someone checks in on me.
6______ I am left alone without anyone checking on me.

A. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points; response #4 = 3 points; response #5 = 4 points; and response #6 = 5 points.

B. Multiply points in "A" by 8.

______
x8
=
______
+

5. How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home?

1______ I am restricted from leaving, even with someone else.
2______ Someone is always with me to help with remembering, decision making or judgment when I go anywhere.
3______ I go to places on my own as long as they are familiar.
4______ I do not need help going anywhere.

C. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points; and response #4 = 3 points.

D. Multiply points in "C" by 8.

______
x8
=
______
+

6. How often do you have difficulty communicating with other people?

1______ I almost always have difficulty.
2______ I sometimes have difficulty.
3______ I almost never have difficulty.

E. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points.

F. Multiply points in "E" by 6.

______
x6
=
______
+

7. How often do you have difficulty remembering important things that you must do.

1______ I almost always have difficulty.
2______ I sometimes have difficulty.
3______ I almost never have difficulty.

G. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points.

H. Multiply points in "G" by 6.

______
x6
=
______
+

8. How much of your money do you control?

1______ None, someone makes all money decisions for me.

2______ A small amount of spending money is given to me periodically.

3______ Most of my money, but someone does help me make major decisions.

4______ I make all my own money decisions (or if married, in joint participation with my partner).

I. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points; and response #4 = 3 points. ______

J. Multiply points in "I" by 4. x4

=

______

K. Add the sums of "B", "D", "F", "H", and "J". =

		MOBILITY
9. On a typical day, how many hours are you out of bed? _____ hours	A. Multiply the number of hours out of bed by 2.	________ +
10. In a typical week, how many days do you get out of your house and go somewhere? ________days	B. Multiply the number of days per week out of the house by 5.	________ +
11. In the last year, how many nights have you spent away from your home (excluding hospitalizations?) ____ none ____ 1-2 ____ 3-4 ____ 5 or more	C. Assign points as follows: no nights out = 0; 1-2 nights out = 10; 3-4 nights out = 15; 5 or more nights = 20.	________ +
12. Can you enter and exit your home without any assistance from someone? yes___ no___	D. For questions #12-#17, assign 5 points for each "yes" response and 0 points for each "no" response.	________ (#12) +
13. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)? ___ yes ___ no		________ (#13) +
14. Can you use your transportation independently? ___ yes ___ no		________ (#14) +
15. Does your transportation allow you to get to all the places you would like to go? ____yes ____ no		________ (#15) +
16. Does your transportation let you get out whenever you want? ___ yes ___ no		________ (#16) +
17. Can you use your transportation with little or no advance notice? ___ yes ___ no	E. Add the sums from "A", "B", "C", and "D". If the total sum is greater than 100, enter 100.	________ (#17) = ☐

		OCCUPATION
18. How many hours per week do you spend working in a job for which you get paid? hours_____	A. Multiply the number of hours working by 2.	________ +
19. How many hours per week do you spend in school working toward a degree or in an accredited technical training program (including hours in class and studying)? ___________ hours	B. Multiply the number of hours in school by 2.	________ +
20. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation? ___________ hours	C. Multiply the number of hours in active homemaking by 2.	________ +
21. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? __________ hours	D. Multiply the number of hours in home maintenance by 2.	________ +
22. How many hours per week do you spend in ongoing volunteer work for an organization? ______ hours	E. Add the number of hours in volunteer work to the number of hours in recreational activities and the number of hours in other self-improvement activities.	________ (#22) +
23. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio._____hours		________ (#23) +
24. How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? Please do not include time spent watching TV or listening to the radio. __________ hours	F. Add the sums of "A", "B", "C", "D", and "E". If the total sum is greater than 100, enter 100.	________ (#24) = ☐

SOCIAL
INTEGRATION

25. Do you live alone? ___Yes ___No

25a. (If you don't live alone) do you live with a spouse or significant other?
___Yes ___No

25b. How many children do you live with? _____

25c. How many other relatives do you live with? _____

25d. How many roommates do you live with? _____

25e. How many attendants do you live with? _____

A. Assign 30 points if living with spouse/partner <u>OR</u> assign 20 points if living with unrelated roommate and/or an attendant.

____
+

26. (If you don't live with a spouse or significant other) are you involved in a romantic relationship?
____ Yes ____ No ____ N/A

B. Assign 20 points if in a romantic relationship, unless points are assigned in "A". If in a romantic relationship <u>and</u> points are assigned in "A", then "B" equals 30 minus "A".

____
+

27. How many relatives (not in your household) do you visit, phone, or write to at least once a month? ________Relatives

C. Add the number of children in household and number of other relatives in household to number of relatives contacted monthly. Multiply by 5. A maximum score for this component is 25 points.

____
+

28. How many business or organizational associates do you visit, phone, or write to at least once a month? ________ Associates

D. If living with more than one attendant, add <u>extra</u> attendants to number of business or organizational associates contacted monthly. Multiply by 2. A maximum score for this component is 20 points.

____
+

29. How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month?______ Friends

E. If living with more than one roommate, add <u>extra</u> roommate to number of friends contacted monthly. Multiply by 10. A Maximum score for this component is 50 points.

____
+

30. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?

___ none ___ 1-2 ___ 3-5 ___ 6 or more

F. Assign points as follows: none = 0 points; 1-2 = 10 points; 3-5 = 15 points; 6 or more = 20 points.

____

G. Add the sums from "A", "B", "C", "D", "E", and "F". If the total sum is greater than 100, enter 100.

=

☐

31. Approximately what was the combined annual income, in the last year, of **all family members in your household**? (consider all sources including wages and earnings, disability benefits, pensions and retirement income, income from court settlements, investments and trust funds, child support and alimony, contributions from relatives, and any other source.)

$______________________.

32. Approximately how much did you pay last year for medical care expenses? (Consider any amounts paid by yourself or the family members in your household and **not reimbursed** by insurance or benefits.)

$______________________.

A. Calculate family size by adding respondent, plus partner (if living with respondent), plus number of children in household, plus other relatives in household.

B. Subtract the unreimbursed medical expenses from the annual income (amount in question #31 minus amount in question #32).

C. Determine poverty level from family size calculated in "A".

D. Divide the value from "B" by the poverty level from "C".

E. Determine points as follows:
If the sum from "D" is:

0.0 to <0.5 = 0 points
0.5 to <1.0 =25 points
1.0 to <1.5 =50 points
1.5 to <2.0 =75 points
2.0 or greater =100 points

ECONOMIC
SELF
SUFFICIENCY

__________.
Family size

__________.
(#31)
minus

__________.
(#32)
=

__________.
divided by

__________.
Poverty level
=

__________.
Convert to points as indicated
=

☐

APPENDIX 9

MPAI-4 Rating Form

Mayo-Portland Adaptability Inventory-4

Muriel D. Lezak, PhD, ABPP & James F. Malec, PhD, ABPP

Name: ______________________________ Clinic # __________________ Date ____________

Person reporting (circle one): Single Professional Professional Consensus Person with brain injury Significant other: _______

Below each item, circle the number that best describes the level at which the person being evaluated experiences problems. Mark the greatest level of problem that is appropriate. Problems that interfere rarely with daily or valued activities, that is, less than 5% of the time, should be considered not to interfere. Write comments about specific items at the end of the rating scale.

For Items 1-20, please use the rating scale below.

0 None	1 Mild problem but does not interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time

Part A. Abilities

1. **Mobility:** Problems walking or moving; balance problems that interfere with moving about

0 1 2 3 4

2. **Use of hands:** Impaired strength or coordination in one or both hands

0 1 2 3 4

3. **Vision:** Problems seeing; double vision; eye, brain, or nerve injuries that interfere with seeing

0 1 2 3 4

4. ***Audition:** Problems hearing; ringing in the ears

0 1 2 3 4

5. **Dizziness:** Feeling unsteady, dizzy, light-headed

0 1 2 3 4

6. **Motor speech:** Abnormal clearness or rate of speech; stuttering

0 1 2 3 4

7A. **Verbal communication:** Problems expressing or understanding language

0 1 2 3 4

7B. **Nonverbal communication:** Restricted or unusual gestures or facial expressions; talking too much or not enough; missing nonverbal cues from others

0 1 2 3 4

8. **Attention/Concentration:** Problems ignoring distractions, shifting attention, keeping more than one thing in mind at a time

0 1 2 3 4

9. **Memory:** Problems learning and recalling new information

0 1 2 3 4

10. **Fund of Information:** Problems remembering information learned in school or on the job; difficulty remembering information about self and family from years ago

0 1 2 3 4

11. **Novel problem-solving:** Problems thinking up solutions or picking the best solution to new problems

0 1 2 3 4

12. **Visuospatial abilities:** Problems drawing, assembling things, route-finding, being visually aware on both the left and right sides

0 1 2 3 4

Part B. Adjustment

13. **Anxiety:** Tense, nervous, fearful, phobias, nightmares, flashbacks of stressful events

0 1 2 3 4

14. **Depression:** Sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism

0 1 2 3 4

15. **Irritability, anger, aggression:** Verbal or physical expressions of anger

0 1 2 3 4

16. ***Pain and headache:** Verbal and nonverbal expressions of pain; activities limited by pain

0 1 2 3 4

17. **Fatigue:** Feeling tired; lack of energy; tiring easily

0 1 2 3 4

18. **Sensitivity to mild symptoms:** Focusing on thinking, physical or emotional problems attributed to brain injury; rate only how concern or worry about these symptoms affects current functioning over and above the effects of the symptoms themselves

0 1 2 3 4

19. **Inappropriate social interaction:** Acting childish, silly, rude, behavior not fitting for time and place

0 1 2 3 4

20. **Impaired self-awareness:** Lack of recognition of personal limitations and disabilities and how they interfere with everyday activities and work or school

0 1 2 3 4

Use scale at the bottom of the page to rate item #21

21. **Family/significant relationships:** Interactions with close others; describe stress within the family or those closest to the person with brain injury; "family functioning" means cooperating to accomplish those tasks that need to be done to keep the household running

0 Normal stress within family or other close network of relationships	1 Mild stress that does not interfere with family functioning	2 Mild stress that interferes with family functioning 5-24% of the time	3 Moderate stress that interferes with family functioning 25-75% of the time	4 Severe stress that interferes with family functioning more than 75% of the time

Part C. Participation

22. Initiation: Problems getting started on activities without prompting

0 None	1 Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time

23. Social contact with friends, work associates, and other people who are not family, significant others, or professionals

0 Normal involvement with others	1 Mild difficulty in social situations but maintains normal involvement with others	2 Mildly limited involvement with others (75-95% of normal interaction for age)	3 Moderately limited involvement with others (25-74% of normal interaction for age)	4 No or rare involvement with others (less than 25% of normal interaction for age)

24. Leisure and recreational activities

0 Normal participation in leisure activities for age	1 Mild difficulty in these activities but maintains normal participation	2 Mildly limited participation (75-95% of normal participation for age)	3 Moderately limited participation (25-74% of normal participation for age)	4 No or rare participation (less than 25% of normal participation for age)

25. Self-care: Eating, dressing, bathing, hygiene

0 Independent completion of self-care activities	1 Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device or require occasional prompting	2 Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)

26. Residence: Responsibilities of independent living and homemaking (such as, meal preparation, home repairs and maintenance, personal health maintenance beyond basic hygiene including medication management) but <u>not</u> including managing money (see #29)

0 Independent; living without supervision or concern from others	1 Living without supervision but others have concerns about safety or managing responsibilities	2 Requires a little assistance or supervision from others (5-24% of the time)	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)

27. *Transportation

0 Independent in all modes of transportation including independent ability to operate a personal motor vehicle	1 Independent in all modes of transportation, but others have concerns about safety	2 Requires a little assistance or supervision from others (5-24% of the time); cannot drive	3 Requires moderate assistance or supervision from others (25-75% of the time); cannot drive	4 Requires extensive assistance or supervision from others (more than 75% of the time); cannot drive

28A. *Paid Employment: Rate either item 28A or 28B to reflect the primary desired social role. Do not rate both. Rate 28A if the primary social role is paid employment. If another social role is primary, rate only 28B. For both 28A and 28B, "support" means special help from another person with responsibilities (such as, a job coach or shadow, tutor, helper) or reduced responsibilities. Modifications to the physical environment that facilitate employment are not considered as support.

0 Full-time (more than 30 hrs/wk) without support	1 Part-time (3 to 30 hrs/ wk) without support	2 Full-time or part-time with support	3 Sheltered work	4 Unemployed; employed less than 3 hours per week

28B. *Other employment: Involved in constructive, role-appropriate activity other than paid employment.
Check only one to indicate <u>primary</u> desired social role: Childrearing/care-giving; Homemaker, no childrearing or care-giving; Student; Volunteer; Retired (Check retired only if over age 60; if unemployed, retired as disabled, and under age 60, indicate "Unemployed" for item 28A.

0 Full-time (more than 30 hrs/wk) without support; full-time course load for students	1 Part-time (3 to 30 hrs/ wk) without support	2 Full-time or part-time with support	3 Activities in a supervised environment other than a sheltered workshop	4 Inactive; involved in role-appropriate activities less than 3 hours per week

29. Managing money and finances: Shopping, keeping a check book or other bank account, managing personal income and investments; if independent with small purchases but not able to manage larger personal finances or investments, rate 3 or 4.

0 Independent, manages small purchases and personal finances without supervision or concern from others	1 Manages money independently but others have concerns about larger financial decisions	2 Requires a little help or supervision (5-24% of the time) with large finances; independent with small purchases	3 Requires moderate help or supervision (25-75% of the time) with large finances; some help with small purchases	4 Requires extensive help or supervision (more than 75% of the time) with large finances; frequent help with small purchases

APPENDIX 10

BICRO-39 Rating Form

BICRO-39

BRAIN INJURY COMMUNITY REHABILITATION OUTCOME SCALES

PATIENT'S QUESTIONNAIRE **POST-INJURY**

Date: ___/___/ 19___ Assessment No: (1) (2) (3) (4)

Your first name: ____________________ Your surname: ____________________

Your date of birth: ___/___/ 19___ Your gender: Male ___ Female ___

Date of your brain injury: ___/___/ 19___

Which of these events caused your injury (please tick):

your head being hit ___
a stroke ___
an illness ___ What was the illness? ____________________
a tumour ___
an overdose ___
other ___ What happened? ____________________
____

This questionnaire helps us understand how much your life has changed as a result of your brain injury. It will also help us to monitor your progress during treatment.

The questionnaire has eight sections which ask about your independence in personal care, mobility, self-organisation, contact with your partner and your own children, contact with your parents and siblings, socialising, productive employment, and psychological well-being.

Please go through the questionnaire and answer all questions according to how you are NOW.

Thank you very much.

PERSONAL CARE

How much help or assistance from other people do you need with ...

	don't do at all	constant help	a lot of help	some help	prompts only	no help/ prompts
1) getting into and out of bed	5	4	3	2	1	0
2) moving from room to room	5	4	3	2	1	0
3) getting to the toilet	5	4	3	2	1	0
4) using the toilet	5	4	3	2	1	0
5) reaching and using the phone	5	4	3	2	1	0
6) reaching and using TV or radio	5	4	3	2	1	0

SCORE (Sum items 1-6): ☐

MOBILITY

How much help or assistance from other people do you need with ...

	don't do at all	constant help	a lot of help	some help	prompts only	no help/ prompts
7) using public transport	5	4	3	2	1	0
8) going to local shops	5	4	3	2	1	0
9) doing laundry (inc. washing, drying, ironing)	5	4	3	2	1	0
10) cleaning the home (inc. vacuuming)	5	4	3	2	1	0
11) shopping (for food, household needs)	5	4	3	2	1	0

How often do you...

	don't do do at all	once or twice a year	several times a year	about once a month	several times a month	once a week or more
12) go out for a walk or to a park	5	4	3	2	1	0

SCORE (Sum items 7-12): ☐

SELF-ORGANISATION

How much help or assistance do you need from other people with ...

	don't do at all	constant help	a lot of help	some help	prompts only	no help/ prompts
13) keeping track of money	5	4	3	2	1	0
14) dealing with your own bank account	5	4	3	2	1	0
15) paying household bills	5	4	3	2	1	0
16) writing official letters (bank, DHSS,...)	5	4	3	2	1	0
17) writing private letters	5	4	3	2	1	0
18) managing appointments	5	4	3	2	1	0

SCORE (Sum items 13-18): ☐

CONTACT WITH PARTNER/OWN CHILDREN

How often do you spend some time with ...

	not applicable or never	once or twice a year	several times a year	once or twice a month	once or twice a week	most or all days
19) your partner or spouse	5	4	3	2	1	0
20) your children	5	4	3	2	1	0

SCORE (Sum items 19-20): ☐

CONTACT WITH PARENTS/SIBLINGS

How often do you spend some time with ...

	not applicable or never	once or twice a year	several times a year	once or twice a month	once or twice a week	most or all days
21) your mother	5	4	3	2	1	0
22) your father	5	4	3	2	1	0
23) a sister or brother	5	4	3	2	1	0

SCORE (Sum items 21-23): ☐

SOCIALISING

How often do you spend time ...

	don't do at all	less than once a week	once or twice a week	several times a week	an hour or so most days	several hours a day
24) socialising with people/family at home	5	4	3	2	1	0

How often do you spend some time with ...

	not applicable or never	once or twice a year	several times a year	once or twice a month	once or twice a week	most or all days
25) relatives *other* than immediate family (i.e. excluding parents, brothers, sisters, partner, own children)	5	4	3	2	1	0
26) your closest friend	5	4	3	2	1	0
27) another long-standing friend	5	4	3	2	1	0
28) a colleague (outside work time)	5	4	3	2	1	0
29) a new acquaintance (made since brain injury)	5	4	3	2	1	0

SCORE (Sum items 24-29): ☐

PRODUCTIVE EMPLOYMENT

How much time do you spend ...

	don't do at all	less than an hour a week	1-4 hours a week	5-10 hours a week	11-20 hours a week	more than 20 hours a week
30) doing paid work	5	4	3	2	1	0
31) doing unpaid or voluntary work	5	4	3	2	1	0
32) studying, training, doing courses	5	4	3	2	1	0
33) looking after children	5	4	3	2	1	0

SCORE (Sum items 30-33): ☐

PSYCHOLOGICAL WELL-BEING

How often do you ...

	almost always	very often	often	some-times	hardly ever	never
34) get impatient with yourself?	5	4	3	2	1	0
35) get angry with other people?	5	4	3	2	1	0
36) feel hopeless about your future life?	5	4	3	2	1	0
37) feel lonely?	5	4	3	2	1	0
38) feel worn out?	5	4	3	2	1	0
39) feel bored?	5	4	3	2	1	0

SCORE (Sum items 34-39): ☐

THANKYOU - YOU HAVE NOW FINISHED

TOTAL SCORES: (for completion by therapist/assessor)

SCALE	SCORE	COMMENTS
Personal Care		
Mobility		
Self-Organisation		
Contact with Partner / Own Children		
Contact with Parents/Siblings		
Socialising		
Productive Employment		
Psychological Well-Being		

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Level of Fatigue Scale.

Below is a 5-point continuum Scale. On this scale, 0 represents no fatigue at all, while 4 represents a level of fatigue being so high that the measure was unable to be completed with the inpatient in one sitting. You may mark a cross at any place along the continuum.

(E.g. 0----------1----------2----------3------X--4)

Please rate the level of fatigue that this outcome measure produced for the inpatient during the current administration:

0----------1----------2----------3----------4

APPENDIX 12

Staff Questionnaire

APPENDIX 12

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Outcome Measures In Brain Injury Rehabilitation
Staff Questionnaire

Date: ______________________

Occupation: _________________________

The following questionnaire has been designed to find out which of the outcome measures used in this study, gave you the most thorough indication of specific activity and participation needs when assessing inpatients.

The first three questions ask you to rank the six measures in an order from best to worst (1 - 6) on certain characteristics. The numbers are along the side of the chart below. Please place a tick under the desired outcome measure title that matches the ranking you have given it.

Questions	Ranking	FIM+FAM	CIQ	DRS	R-CHART	MPAI-4	BICRO-39
1. If you think about the items included in each outcome measure, which measure do you feel best collects information that easily identified goals for rehabilitation.	1						
	2						
	3						
	4						
	5						
	6						
2. How easy is it for inpatients to understand the wording of the questions used in these measures?	1						
	2						
	3						
	4						
	5						
	6						
Questions	Ranking	FIM +FAM	CIQ	DRS	R-CHART	MPAI-4	BICRO-39
3. Compared to the FIM+FAM, rank the other five measures according to how quick and easy the measures were to score and interpret.	1						
	2						
	3						
	4						
	5						

4. In the spaces below, could you please note one good attribute and one negative attribute for each of the outcome measures. Please write no more than a sentence for each.

FIM + FAM:

1. (postitive) ______________________________
2. (negative) ______________________________

Community Integration Questionnaire:

1. (positive) ______________________________
2. (negative) ______________________________

Disability Rating Scale:

1. (positive) ______________________________
2. (negative) ______________________________

Mayo-Portland Adaptability Inventory:

1. (positive) ______________________________

2. (negative) ____

The Revised Craig Handicap Assessment & Reporting Technique:

1. (positive) ____

2. (negative) ____

The Brain Injury Community Rehabilitation Outcome Scale

1. (positive) ____

2. (negative) ____

5. If you could choose 2 of the measures to continue using with inpatients in order to identify rehabilitation needs and to evaluate outcomes, which 2 would you choose and why? Please tick the two of your choice:

☐ FIM + FAM

☐ CIQ

☐ DRS

☐ R-CHART

☐ MPAI - 4

☐ BICRO – 39

Comments:

I would like to take this opportunity to thank you for your time and effort during this study.