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Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook

Heather Yekel  
*University of North Dakota*

Breana Medlock  
*University of North Dakota*

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TRAUMATIC BRAIN INJURY (TBI):
CAREGIVER AND FAMILY EDUCATION HANDBOOK

by

Heather Yekel, MOTS
Breana Medlock, MOTS

Advisor: Scott Johnson, OTD, OTR/L, ATP

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of the
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This Scholarly Project Paper, submitted by Heather Yekel and Breana Medlock in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Faculty Advisor

4-21-06

Date
PERMISSION

Title: Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook

Department: Occupational Therapy

Degree: Master’s of Occupational Therapy

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ABSTRACT

Life can be very confusing for the friends, family member(s), and caretaker(s) of those individuals who are diagnosed with a Traumatic Brain Injury (TBI). The people who live with and care for the individual with a TBI want to know how they can help and what they can do to speed up the recovery. They also want to know what they can expect from their loved one, how much time the recovery will take, and what is causing the changes in their behavior?

A review of the literature was conducted and professionals, who are currently providing services to individuals diagnosed with a TBI, were interviewed. It was identified that information for TBI provided to family member(s) and caregiver(s) is lacking, the caregiver(s) and family member(s) need user-friendly information and education about the effects of traumatic brain injury in the care and treatment of their loved one. Based upon these findings a Traumatic Brain Injury Caregiver and Family Education Handbook was developed.

The (TBI) Handbook is designed as a guide for caregiver(s) and family member(s) as they transition though the process of assessment and treatment of their family member who has been diagnosed with a TBI. The Handbook guides the caretaker through the rehabilitation process and offers suggestions of activities that may occur and expectations for outcomes. The Handbook includes the following information:
definitions of TBI and related terms; etiology of TBI; definitions of treatment team members and how to can utilize them as resources; what differences to expect in the brain injured individual; what to expect from treatment; expectations for return to school, work, and driving; and the importance of emotional support for the family member(s) and caregiver(s).

The outcome of this scholarly project is a tool for practicing Occupational Therapists (OT), to provide to the family member(s) and caretakers of individuals diagnosed with a TBI. This will benefit the individual diagnosed with a traumatic brain injury by having activities that carry over the intervention provided by the OT in the clinic and allow the family to become more involved in understanding and meeting their needs. The handbook is based on current evidence based literature and current best practice methods. The information compiled will allow the family member(s) and caretakers to be educated and empower them to feel as though they are participating members in the individual diagnosed with a brain injury's recovery process.
CHAPTER I
INTRODUCTION

According to Gutman (2002) and Nolan (2005) there are currently 5.3 million individuals living with disabilities related to TBI and 373,000 incidences of traumatic brain injuries each year. Life can be very confusing for the friends, family member(s), and caretakers of those individuals who are diagnosed with a Traumatic Brain Injury (TBI). The people who live with and care for the individual with a TBI want to know how they can help, and what they can do to speed up the recovery. They also want to know what they can expect from their loved one, how much time the recovery will take, what is causing the changes in their behavior?

An exploration of the current literature was conducted for evidence based practice information regarding TBI. Based upon the literature and discussions with current practicing occupational therapists, a Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook was designed for the caregiver(s) and family member(s) of an individual with a brain injury. The Handbook utilizes the Occupational Adaptation Theoretical Frame of Reference (FOR). According to Schkade and Schultz:

The Occupational Adaptation process consists of a series of actions and events that unfolds as an individual is faced with an occupational challenge that occurs as the result of person/environment interactions within an occupational role. This process exists to enable the individual to respond adaptively and masterfully, that is, to meet both self-produced (internal) role expectation and environmentally produced (external) role expectations. (2003, p. 185)
In this case the occupational challenge is caring for the individual with the TBI. The role is of caretaker, but may also be a parent, spouse, child, or sibling. The expectations of this role are presented and discussed in chapters two and four and it is not likely the individual, who is the caretaker, is informed about TBI prior to the injury. The Handbook guides the caretaker through the rehabilitation process and offers suggestions of activities that may occur and expectations for outcomes. The Handbook assists the caretaker to reflect on the process of caretaking and adapt their methods to meet the needs of the brain injured individual as well as their own.

A comprehensive educational manual for family member(s) and caretakers of individuals with TBI is a great resource for Occupational Therapists. The outcome of this scholarly project is a tool for practicing Occupational Therapists (OT) to provide to the family member(s) and caretakers of individuals diagnosed with a TBI. This will benefit the individual diagnosed with a brain injury by having activities that carry over the intervention provided by the OT in the clinic and allow the family to become more involved in understanding and meeting the needs of the individual diagnosed with a brain injury. The information will be based on current evidence based literature and current best practice methods. The information compiled will allow the family member(s) and caretakers to be educated and empower them to feel as though they are participating members in the individual diagnosed with a brain injury's recovery process.

Chapter one concludes with terminology that is used throughout all five chapters of the scholarly project as well as a brief summary of the chapters that follow. The resources for terminology used included: Gutman, 2001; Khan, Baguely & Cameron, 2003; Nolan, 2005; Perlesz, Kinsella & Crowe, 2000; Radomski, 2002; Wade, Taylor, Drotar, Stansin, Yeates & Minich, 2002.
Terminology

This terminology was adapted from many different sources and is referred to and referenced later in this document.

**TBI:** Insult to the brain, not degenerative or congenital, that is caused by an external physical force. This insult may produce a diminished or altered state of consciousness and resultant impairment of cognitive, behavioral, emotional or physical functioning.

- This means an injury caused by an outside source such as falling and hitting the head or something striking the head such as a ball in sports.

**Blunt Trauma:** The most common cause of TBI and is frequently the result of motor vehicle accidents and bicycle crashes, pedestrian vs. auto impacts, falls, sports, and assaults.

**Penetrating TBI:** Can be the result of any sharp or blunt object penetrating the scalp and skull, exposing and entering the brain.

**Blast:** The result of a combination of blunt and penetrating forces.

**Open Head Injury:** Injury in which the skull is fractured or penetrated.

**Closed Head Injury:** Injury in which the skull remains intact.

**TBI as Primary Injury:** Occurs as a result of the initial impact to the head, which directly damages the neuronal tissues. Can be classified as focal or diffuse.

**Focal Injury:** Commonly caused by penetrating wounds and is often the result of an open head injury.
Contusion: May be caused by a skull fracture or shaking of the brain back and forth within the skull. This causes bruising of brain tissues when the injured area swells and blood is released from broken blood vessels. This type of injury is called contrecoup.

Diffuse Injury: Is not localized, but rather involved widespread damage to brain tissue. These injuries, termed diffuse axonal injuries result in coma.

TBI Secondary Injury: The result of normal physiologic responses to primary injury. Cerebral edema, hemorrhage, biochemical response to injury, infection, and increased intracranial pressure are among the most common physiologic responses that can cause secondary injury.

- If the TBI is resulted from a direct impact and is the main resulting injury it is a primary injury. If injuries occur as a complication from the initial injury which caused the TBI it is considered a secondary injury.

Glasgow Coma Scale: generates a score between 3 and 15 based on a person’s abilities in eye opening and motor and verbal function. The GCS gives a prognosis for survival rather than for functional outcomes.

Mild TBI: Induced physiological disruption of brain function as manifested by at least one of the following: any period of loss of consciousness, any loss of memory for events immediately before or after the accident, any alteration in mental state at the time of the accident, focal neurological deficit that may or may not be transient, initial Glasgow Coma Scale Score of 13 to 15.

Moderate TBI: Initial Glasgow Coma Scale score of 9 to 12; post traumatic amnesia of 1 to 24 hours.
Severe TBI: Loss of consciousness longer than 6 hours; initial Glasgow Coma Scale score of 8 or less.

Post Traumatic Amnesia: The period of time in which the brain is unable to lay down continuous day to day memory.

Concussion: Cerebral concussion is defined as a transient, temporary, neurological dysfunction as a result of a force applied to the brain. Cerebral concussions may be mild or moderate.

Mild Concussion: Results in temporary focal (depending on the area of the brain affected) neurological dysfunction, without any loss of consciousness or loss of memory.

Moderate Concussion: Also called classic concussion, usually results in the temporary focal neurological dysfunction such as seen in mild concussion, as well as unconsciousness and memory loss. Recovery from moderate concussion can take minutes, to hours, to days.

Post-Concussion Syndrome: includes symptoms such as irritability, fatigue, headache, difficulty concentrating, dizziness, and memory problems.

Post Traumatic Stress Disorder: PTSD is defined as “a syndrome that develops after a person sees, is involved in, or hears of an extreme traumatic stressor. The person reacts to this experience with fear and helplessness, persistently relives the event and tries to avoid being reminded of it” (Sadock & Sadock, 2004, p. 232)

Orientation: awareness of time, place, and person. This means the individual can identify where they are; what time of day, year, and month it is; and who they and other important people are.
Chapter II will provide a review of the literature that guided the designing of the final product. Chapter III introduces and explains the methodology that was used to gather the information for the development of the caregiver guide. Chapter IV is the Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook in its entirety. Chapter V is a summation of information and recommendations for further development and research.
CHAPTER II

REVIEW OF THE LITERATURE

Introduction

When a person is affected by a traumatic brain injury (TBI,) family member(s) are often their caregiver(s). Recovery is often a long process requiring interaction between the medical health professionals, the individual with the TBI, and the caregiver(s). Family member(s) are quickly thrown into the position of caregiver with little training or education while trying to gain a sense of equilibrium with their own emotions and fears. Their new position will bring questions ranging from; what is a TBI to how can I help and what are the chances they will return to previous functioning levels? There is a plethora of information available, but there are few if any comprehensive guides to TBI recovery for family member(s). There are none that an OT can use to provide to family member(s) and caretakers with information that will educate and empower them to feel as though they are participating members in the individual diagnosed with a brain injury's recovery process. Also, there was limited information to teach the caregiver(s) how to assist the individual diagnosed with a brain injury with activities that carry over the intervention provided by the OT in the clinic. This will also allow the family to become more involved in understanding and meeting the needs of the individual diagnosed with a brain injury.
Foundational Terminology

Based upon the literature review, there were several primary terms identified to answer the basic questions a caregiver or family member may have regarding TBI and are identified as foundational to gaining an understanding of the medical intervention. These terms are presented and defined in this section.

Radomski (2002) defines traumatic brain injury (TBI) as “insult to the brain, not degenerative or congenital, that is caused by an external physical force. This insult may produce a diminished or altered state of consciousness and resultant impairment of cognitive, behavioral, emotional or physical functioning” (p. 856). Gutman (2001) states “There are two basic categories of TBI: closed head injury (CHI), in which the skull remains intact and open head injury (OHI) in which the skull is fractured or penetrated” (p. 671). A skull fracture or shaking of the brain back and forth within the skull may result in a contusion. Kernich (2004) explained that a TBI can cause bruising of brain tissues. The injured area is swollen and broken blood vessels release blood into the brain causing a countercoup type injury.

A TBI may be caused by different forces including: blunt, penetrating, or blast. Nolan (2005) reports that “blunt trauma is the most common cause of TBI, and is frequently the result of motor vehicle accidents and bicycle crashes, pedestrian versus auto impacts falls, sports, and assaults” (p. 189). A penetrating TBI can be the result of any sharp object blunt object penetrating the scalp and skull, exposing and entering the brain. A blast TBI is the result of a combination of blunt and penetrating forces.

A TBI can also be classified as primary or secondary injury. Nolan, (2005) states that primary injury occurs as a result of the initial impact to the head, causing damage to
neuronal tissues. Secondary injury is the result of normal physiologic responses to primary injury including: cerebral edema, hemorrhage, biochemical response to injury, infection, and increased intracranial pressure (Nolan, 2005). This means that primary injuries are those that are a direct result of the impact causing brain damage and secondary injuries are those that occur due to the brain’s response to these changes (i.e., infection of the brain can occur due to an open head wound).

To further break down the information into additional categories, a primary TBI can be classified as focal or diffuse. Focal lesions include contusions and lacerations of the brain that occur when the brain hits the skull and scrapes over the irregular bony structures at these locations (frontal and temporal lobes). Diffuse brain injuries are those that involve large, generalized areas of the brain. Injuries occurring while the body/head are moving, such as during motor vehicle accidents and falls. It is these type of accidents that produce acceleration, deceleration, and rotation of the brain inside the skull. The brainstem is more stable than the cerebrum. The cerebrum rotates around the brainstem during impact, causing a stretch or shear force on the long axons that transmit information throughout the brain and brainstem. These injuries, termed diffuse axonal injuries, often result in coma. (Radomski, 2002)

Physicians use the Glasgow Coma Scale (GCS) as a determinant of severity of brain injury. This is a term used by most health care providers serving brain-injured individuals. The scores derived are meant to give a realistic expectation of survival. Khan et al. (2003) state:

The GCS generates a score between 3 and 15 based on a person’s abilities in eye opening and motor and verbal function. It is a quick and easy tool used to assess the severity of traumatic brain injury in the acute setting. The GCS gives a prognosis for survival rather than for functional outcomes. (p. 293)
Ruff (2005) reports “This scale allowed for repeated ratings of severity at the scene, during transport, in the emergency department and throughout hospitalization” (p. 5).

The GCS is used to classify a TBI into mild, moderate, or severe categories. Radomski (2002) defines these as:

Mild: trauma induced physiological disruption of brain function as manifested by at least one of the following: any period of loss of consciousness, any loss of memory for events immediately before or after the accident, any alteration in mental state at the time of the accident, focal neurological deficit that may or may not be transient, initial Glasgow Coma Scale score of 13 to 15. Moderate: Initial Glasgow Coma Scale score of 9 to 12; posttraumatic amnesia of 1 to 24 hours. Severe: loss of consciousness longer than 6 hours; initial Glasgow Coma Scale score of 8 or less. (p. 857)

The Rancho Los Amigos Levels of Cognitive Functioning Scale is another scale that can be used at anytime following an injury. This scale uses behavioral observations to categorize an individual diagnosed with a brain injury’s level of cognitive function and awareness. The scale scores range from no response to purposeful and appropriate. These scores are not a predictor of outcome, but rather a statement of response at the time (Radomski, 2002).

This information may help those with individuals diagnosed with a brain injury to understand the following related disorders. These disorders are those that might be present in the different stages of these scales.

Related Syndromes and Disorders

Post traumatic amnesia, post concussion syndrome, cerebral concussion and post traumatic stress disorder are common areas of related syndromes and disorders an individual with a brain injury could experience. They are important to educate a
1. Post traumatic amnesia (PTA) is common following a TBI. Khan et al. (2003) state “The duration of PTA is the best indicator of the extent of cognitive and functional deficits after TBI. PTA is defined as the period of time in which the brain is unable to lay down continuous day to day memory” (p. 293).

2. Postconcussion syndrome is common among individuals with TBI. Nolan (2005) indicates that this syndrome can include: irritability, fatigue, headache, difficulty concentrating, dizziness, and memory problems. These symptoms can arise days, months, or years post injury. These problems can be debilitating if not recognized and treated appropriately. This syndrome can also lead to insomnia, anxiety, and depression. Cerebral concussion is defined as: “a transient, temporary, neurological dysfunction as a result of a force applied to the brain” (Nolan, 2003, p. 191).

3. A cerebral concussion can be mild or moderate. Mild concussions result in temporary focal brain dysfunction, without loss of consciousness or memory. Moderate concussions (classic concussions) usually result in temporary focal brain dysfunction as well as unconsciousness and memory loss. Recovery from a moderate concussion can last minutes, to hours, to days. (Nolan, 2003)

4. Post-traumatic stress disorder (PTSD) does occur in some individuals diagnosed with a brain injury. PTSD is defined as “a syndrome that develops after a person sees, is involved in, or hears of an extreme traumatic stressor. The person reacts to this experience with fear and helplessness, persistently relives the event and tries
to avoid being reminded of it” (Sadock & Sadock, 2004, p. 232). This may be a concern for family member(s) of individuals who have suffered a brain injury because the family member(s) can not assist the individual if they are not aware of what is happening or that this is a common issue. Research has found that it is more likely for an individual who was not unconscious to experience symptoms of PTSD (Glaesser, Neuner, Lütgehetmann, Schmidt & Elbert, 2004, p.1).

The previous information assists the treatment team in determining the needs of the individual at their current stage. That information allows the care team to provide a good estimate of the individual diagnosed with a brain injury’s expectations at present. Meaning, if the individual diagnosed with a brain injury is at a certain stage on the Glasgow scale, we can predict what kinds of behaviors they will present. This information should also be known by the caregiver(s) and family member(s) so they can assist with the rehabilitation of the individual diagnosed with a brain injury.

Cognitive Deficits

Changes in cognitive (thought process) ability affect the brain injured individuals ability to make choices and functioning in every day tasks. “TBI can affect competency to make important financial decisions, to comply with medical management, to give informed consent, and to make other life decisions” (Khan et al., 2003, p. 295).

According to Goverover and Hinojosa (2002) cognitive and perceptual impairments are common with TBI individual diagnosed with a brain injurys. Every day tasks require deductive reasoning and categorization skills. These abilities may be impaired in brain injured individuals, and their skills may need to be refined before moving on to more involved tasks.
Brain injury and resulting impairment of cognition often results in concrete thinking. Abstract concepts and generalization of ideas and skills from one task to another may be difficult. For example an individual may be able to brush their hair but not brush their teeth. The abilities are present, but without instruction the individual who is brain injured cannot generalize their abilities to the task at hand. This may be frustrating for family member(s) or any other individual who knew the individual pre-injury, but the behavior is to be expected. (Gutman, 2001)

An individual’s brain injury and resulting cognitive deficits can range from severe deficits to high levels of cognitive ability. Gutman (2001) states:

Advanced-level individual diagnosed with a brain injury with TBI who demonstrate high level cognitive skills often display subtle cognitive deficits in the areas of organization, planning, sequencing, and short term memory. Activities such as establishing a monthly budget to live independently in the community and negotiating the community public transportation system to pay a bill at the electric company provide a context for cognitive retraining to address subtle cognitive deficits. (pp. 693-694)

Deficits in the skills areas of; organization, planning, sequencing, and short term memory, are common in individuals with TBI. These skills are necessary for functioning in every day life and are usually addressed in rehabilitative therapy. Assistive devices may be used as rehabilitative tools for these deficits, which may be either low tech or high tech. Low tech devices may include a memory journal, reminder notebook, or day planner. High tech devices may include cognitive retraining software programs or scheduling software on a personal computer and personal digital assistants (PDA’s). (Mateer, Sira, & O’Connell, 2005)
Computer assisted cognitive retraining (CACR) has been used as an effective addition to traditional rehabilitation techniques. However, there is some controversy surrounding the use of cognitive retraining computer software. Lynch (2002) states:

Training needs to be focused, structured, monitored, and as ecologically relevant as possible for optimum effect. Transfer of training or generalizability of skills remains a key issue in the field and should be considered the key criterion in evaluating whether to initiate or continue CACR. (p. 446)

Orientation to time, place, and person means that an individual can identify: where they are; what time of day, year, and month it is; and who they and other important people are. When an individual is in the acute stage of recovery from TBI they may have deficits in orientation. According to Alderson & Novak (2002) if an individual gains orientation before discharge from an acute setting they achieve higher scores on functional measures. Recovery of orientation has been shown to predict rehabilitation outcomes.

Behavioral and Social Deficits

Unexpected results of head trauma are usually behavioral and social deficits. Gutman (2001) explains that social roles are a large contributor to self-image. When a person becomes brain injured they lose most of their social roles and the activities that support those roles.

Sherer, Nakase–Thompson, Yablon, & Gontkovsky (2005) explain that agitation is common during early TBI recovery and may interfere with rehabilitation compliance. The agitation can also pose safety problems for the rehabilitation staff and the patient. For these reasons rehabilitation professionals have been interested in agitation assessment after TBI.
Gutman (2001) adds “behavioral disturbance is common in TBI recovery. Most behavioral disturbances are organically based and result from specific neurological damage” (p. 684). Patients may exhibit behavioral problems from verbally and physically combative to mildly confused and agitated. Patients demonstrating severe confusion demonstrate impatience, irritation, and physical and verbal combativeness. These deficits are not by choice of the individual diagnosed with a brain injury and should not be taken personally by anyone around them. It may be difficult for those surrounding the individual with TBI who do not understand or accept this as a symptom. “Behavioural [sic] changes may alienate family and friends, with families sometimes perceiving the person as a “difficult stranger”... Ignorance and misperceptions of families, coworkers and healthcare professionals about the effects TBI may make matters worse” (Khan et al., 2003, p. 295).

Social disability (deficits in ability to participate in social activities) may also occur when an individual experiences brain injury. “A combination of deficits leads to greater degree of social disability than would be expected from isolated single deficits” (Khan et al., 2003, p. 295). “Social inappropriateness and disinhibition are also common behavioral problems in some patients with TBI and may involve using obscenities, making indiscriminate sexual advances to staff or strangers in the community, and removing clothing in public settings” (Gutman, 2001, p. 684). Caregiver(s) may be curious as to when this will stop. Patients experience agitation and confusion during the subacute recovery period for weeks or even months. These behaviors may be replaced with more appropriate actions as the neurological recovery progresses. Some brain injuries result in severe behavioral disturbances that do not change with time. It may be
necessary to provide a behavioral management program for patients displaying long term
and chronic behavioral problems. Gutman (2001)

Recovery Expectations

Throughout the recovery process caregiver(s) and individuals with TBI are often
confused about what is happening because they did not expect the range of symptoms
that are secondary to a head injury. Chestnut, Carney, Maynard, Mann, Patterson &
Helfand (1999) defined four phases of life for adult survivors of moderate to severe TBI
including: 1) pre-injury, 2) medical treatment, 3) rehabilitation, and 4) survivorship. The
pre-injury phase is the time of life that occurred prior to the injury and includes the
individual’s experiences, skills, abilities, personality and attributes. The medical
treatment phase includes the acute and the intensive periods of treatment. The medical
treatment phase consists of the gurney to the intensive care unit (ICU) where a diagnosis
is made and treatment begins, and then to the ICU to an acute hospital discharge where
diagnosis and treatment are ongoing. The rehabilitation or recovery phase consists of
education and training and conditioning. This phase could last for months or years where
assessment of abilities and deficits and training is ongoing. The main areas of focus of
the rehabilitation phase include: “retraining in activities of daily living, pain
management, cognitive and behavioural [sic] therapies, pharmacological management,
assistive technology, environmental manipulation, as well as family education and
counseling” (Khan et al., 2003, pp. 293-294). Retraining in daily living activities for
home and community living, family support, education, and counseling are vital and
likely to be needed for a prolonged period (Khan et al., 2003). The survivorship stage
or survival phase is where the individual attempts to establish and live a new life. In this phase personal, social, and quality of life adjustments are made (Radomski, 2002).

The time frame of recovery is variable, due to the wide range of injuries that could occur and symptoms that present there is no specific time frame available. Khan et al. (2003) suggest “studies of recovery from TBI show ongoing improvements for at least 2-5 years after injury” (p. 292). Individuals who experience a mild traumatic brain injury and do not require inpatient rehabilitation, have reported variable recovery times.

Patients commonly report cognitive and behavioral changes from which they recover within 3-6 months, 10%-15% remain symptomatic in the longer term with a persisting post-concussion syndrome: physical complaints including headache, cervical pain, vestibular symptoms; changes in taste and hearing; difficulty with attention and memory; and irritability, insomnia and sleeping difficulties. Interpersonal relationships and work may also be affected. (Khan et al., 2003, p. 294)

Return to Vocation and Education

Cognitive and behavioral deficits can affect a person’s ability to return to everyday occupations. Some of the most important and time-consuming occupations include vocation (work) and education (school). While recovering from a TBI one of the most common questions for the individual diagnosed with a traumatic brain injury and their family is when can they return to school or work, and how will they perform. Due to the wide range of deficits that can occur with a TBI, it is difficult to give a specific answer. There are some predictors of abilities and a general time frame for their return to school and/or work.

Vocation

Before returning to work, individuals must re-establish their competence in self maintenance roles. Post-acute rehabilitation aimed at return to work should focus on
work behaviors and habits such as punctuality, thoroughness, response to feedback, and the ability to take and use notes (depending on the vocation).

The therapist will help the individual, with a brain injury, to establish realistic vocational goals. Pre-vocational therapy will focus on the individual’s physical and cognitive abilities. Individuals with a TBI may benefit first trying volunteer jobs to employ compensatory cognitive strategies and build their endurance and work tolerance.

“It has been well documented that the return to work after a moderate to severe brain injury is generally unsuccessful” (Gutman, 2001, p. 692). In many cases the individual may not be able to return to their previous level of ability and therefore will not return to their previous employment. A referral may be made to a vocational therapist to assist the brain injured individual in finding a job that matches their current abilities. An advanced-level patient with TBI may be evaluated for return to work. It is important to remain realistic in planning for vocation.

Programs such as a Medical/vocational case coordination system (MVCCS) provide “(1) early case identification and coordination, (2) appropriate medical and vocational rehabilitation interventions, (3) work trials, and (4) supported employment interventions including job coaching” (Malec, Buffington, Moessner, & Degiorgio, 2000, p. 1007). An outcome study of the MVCCS coordination system identified that an:

- MVCCS optimized vocational outcome after BI (brain injury).
- Time since injury and impairment/disability best predicted vocational placement.
- Level of initial placement best predicted employment status of follow-up.
- Persons with greater disability required more extended time and more extensive rehabilitation services before placement. (Malec et al., 2000, p. 1007)
Driving

Driving is a task that most adults are required to do in their daily lives for survival and it is a challenging task. After a TBI, there is often curiosity about returning to this vital task due to cognitive impairments. “Many states require physicians to report to the Department of Motor Vehicles any patient who has lapses of consciousness, seizure disorders, and cognitive, visual and perceptual dysfunction caused by TBI” (Gutman, 2001, p. 691). Regulations surrounding a TBI often mean the driver’s license will be revoked until assessment confirms that the patient is not posing a safety risk to self or others while driving. (Gutman, 2001)

Deficits such as visual processing disorders, figure-ground discrimination dysfunction, and impulsivity affect the individual diagnosed with a brain injury’s ability to drive a motor vehicle. These deficits cause hesitation during driving maneuvers, unsafe stops, inability to identify stop signs and traffic signals, inability to locate the gearshift, and aggressive driving rather than defensive driving. (Gutman, 2001)

These abilities must be evaluated before an individual can legally return to driving a motor vehicle. “Two types of driving evaluations are completed for patients with TBI: A clinical assessment (evaluation of the patient’s visual, cognitive, perceptual and physical status as it relates to driving) and an on-road assessment” (Gutman, 2001, p. 691).

Caregiver(s) spend the most time with the individual diagnosed with a brain injury and are therefore an important team member in the rehabilitation process. In the case of driving, researchers have found “significant other’s perceptions of the patient’s fitness to drive were the strongest predictor of patient’s driving status and driving
frequency” (Coleman, Rapport, Ergh, Hanks, Ricker, Millis, 2002, p. 1415). There were other indicators of post-injury driving safety including: years post-injury, disability at discharge, and current neuropsychological functioning.

**Education**

The return to school is similar to returning to work, it is an occupation that consumes much of the time of the individual diagnosed with a brain injury. The child may have cognitive deficits hindering academic ability.

Upon discharge from the hospital, health professionals should provide the schools with information about TBI so that children returning to school receive necessary supports. In addition to the professionals input, schools also rely heavily on the parents (caregiver(s)) of the individual diagnosed with a brain injury to inform them of any deficits and needs. Hawley et al. (2004) stated there is a necessity to including the school in the team approach of rehabilitation.

Modifications and related educational services may be necessary for success in the school setting. Educating the school about the child’s deficits, and remaining an active participant in their educational integration is key to success. A research study including 67 school aged children with TBI (35 mild, 13 moderate, 19 severe) found:

One third of teachers were unaware of the TBI. On return to school, special arrangements were made for 18 children (27%). Special educational needs were identified for 16 (24%), but only six children (9%) received specialist help. Two thirds of children with TBI had difficulties with school work, half had attention/concentration problems and 26 (39%) had memory problems. Compared to other pupils in the class, one third of children with TBI were performing below average. On the CMS (Children’s Memory Scale), one third of the severe group were impaired/borderline for immediate and delayed recall of verbal material, and over one quarter were impaired/borderline for general memory. Children in the severe group had a mean full-scale IQ significantly lower than controls. Half the TBI group had a reading age ≥ 1 year below their
chronological age, one third were reading ≥ 2 years below their chronological age. (Hawley et al., 2004, pp. 136-137)

Most of the research has been conducted for elementary age children, but the suggestions in research may apply to adolescents and college aged students. Return to school predictors and outcomes after a TBI is a topic that may need more investigation.

Family Involvement

Family member(s) may display many emotions including grief, anger, and confusion in response to the injury and resulting deficits of a TBI.

Involving family member(s) in therapy is a particularly beneficial way of providing information about the loved one’s condition while alleviating their confusion and anger. Family member(s) should be involved in therapy from the beginning of the patient’s hospital stay” (Gutman, 2001, p. 689).

When a brain injury occurs the dynamics of the family will change. Children may become caretakers, or a parent may take on more of a caretaker role than previously. It is a given that an individual with TBI will require more attention than the other members of the family, and this has been proven to cause stress. Literature states “Patterns of adaptation over time varied across groups but indicated long standing injury related stress and burden in the severe TBI group... Severe TBI results in persistent caregiver stress for a substantial proportion of families” (Wade, Taylor, Drotar, Stancin, Yeates, & Minich, 2002, p. 96).

Complete findings of a study involving all family member(s) including primary, secondary, and tertiary cares state that a significant proportion of the family member(s) were not distressed psychologically and reported good family satisfaction. Perlesz,
Kinsella, & Crowe (2000) found that individuals with a TBI are at greater risk of poor psychosocial outcome than their caretakers and relatives. Of the family member(s) who take on the role of caretaker for the brain injured individual, the primary caregiver(s) are at greatest risk of poor psychosocial outcome. Secondary and tertiary caregiver(s) also display high levels of distress.

The most distressed group of relatives was primary carers, most often mothers and wives; those who bear the greatest responsibility for caring for their relative with head injury. . . Wives were significantly angrier and less satisfied with their families than were mothers. (Perlesz, Kinsella, & Crowe, 2000, p.918)

LoBello, Underhill, Valentine, & Stroud (2003) found that family satisfaction is affected by interactions among family member(s). The more positive interactions among family member(s), the higher the level of overall family satisfaction, which generally contributes to a higher quality of life.

*Cost*

The cost of medical care can be a burden for some families. Most caregiver(s) are frightened about the cost of a lifetime injury such as a TBI. There are some gaps in the literature in this area. The OT students were not able to locate the current cost to provide care for one individual diagnosed with a traumatic brain injury and further it is difficult to report costs because each individual’s cost will vary with severity of injury and length of treatment. A study of costs of TBI injuries in children reports “the average lifetime cost per survivor of TBI requiring hospitalization was $111,578, with the average cost per fatality being $454,717” (Brener, Harman, Kelleher, & Yeates, 2004, p. 405).
The Need for a Broad Range of Interventions

When the rehabilitation process begins there will be many health care professionals using different modes of intervention. The consumer can expect to be treated on a physical, cognitive, and emotional level. Research by Mateer, Sira, & O’Connell (2005) find “combining cognitive and emotional interventions was not only effective but also even more valuable than previous treatment approaches aimed exclusively at one domain” (p. 62)

Research is currently suggesting that multimodal approaches are necessary to meet the many needs of the brain injured individual. Mateer (2005) states that a combination of therapies (neuro-rehabilitation, pharmacotherapy, and cognitive behavioral) is needed. Many rehabilitation programs incorporate multiple interventions to meet these needs.

Some programs incorporate the following interventions: attention training; memory compensations; skills training; feedback on performance; psychoeducation aimed at providing information and support; monitoring of emotional response to difficulties; stress management; confidence building; psychotherapy aimed at increasing self-awareness, acceptance, and adjustment (Mateer et al., 2005, p. 64).

A multi-dimensional approach would include social participation and community integration. Cicerone (2004) states:

to date, few studies have included measures of social participation or community integration as outcome measures after TBI rehabilitation. A small number of studies suggest that postacute TBI rehabilitation can produce improvements in participation and community integration. However, a considerable amount of variability in rehabilitation outcomes may be apparent. . . Rehabilitation may exert its benefits not only by facilitating improvements, but also by preventing declines in community functioning. Subjective well-being and quality of life have generally been ignored as TBI rehabilitation outcomes. There is considerable evidence that participation and subjective well-being represent distinct and dissociable outcomes after TBI, which may reflect the importance of
patients' preferences and values in evaluating the effectiveness of rehabilitation. (Cicerone, 2004, p. 494)

Therefore consumers may report better outcomes of treatment if they had integrated these services into their service plan. If consumers were able to be successful in these areas they may feel their overall treatment was successful.

Environmental adaptation is an intervention that may lead to greater life satisfaction and success in rehabilitation for the individual diagnosed with a brain injury. Whiteneck, Gerhart, & Cusick (2004) state: "Those reporting a greater impact from environmental barriers also reported lower levels of participation and life satisfaction" (p. 191). This could be part of an integrated treatment approach that would lead to higher participation and life satisfaction.

Traditional Rehabilitation Services: Phillips, Greenspan, Stringer, Stroble, & Lehtonen (2004) found "traditional rehabilitation services, such as physical therapy were far more likely to be used, than nontraditional services, such as psychological counseling, in spite of the high level of cognitive and social disability associated with traumatic brain injury" (p. 217). There are many factors dictating which services the brain injured individual will receive including: nature of the survivor's insurance, service availability in the local area, patient and family preferences, injury severity, and local care practices. Also instrumental in services provided is the current trend in healthcare to reduce costs from Medicare and managed care organizations leading to shorter hospital stays (Phillips, Greenspan, Stringer, Stroble, & Lehtonen, 2004). Even though there are many factors involved which decrease services, it is important to educate the consumers and
caregiver(s) on the outcomes related to a multi-dimensional approach so they may seek other services if they wish.

Each injury and individual is unique, meaning each treatment approach should be individual diagnosed with a brain injury specific. However, treatment should meet all needs of the individual diagnosed with a brain injury for best outcomes. Nortje & Menon (2004) state “improved monitoring techniques emphasize the need for individualization of therapeutic interventions” (p. 711). “Standardized intervention may at one time be beneficial, while at another time the same intervention may be useless or even harmful” (Warner, & Borel, 2004, p. 1208). This is in contrast with the previous information that a multi-modal approach is the best approach because while it is best to include all necessary therapies, not every individual will need all available therapies.

In order to find the best approach to treatment the team must work together to inform the caregiver of the needs of the individual with a TBI. The caregiver in return would need to have a working knowledge of the team members and their roles in treatment. The caregiver(s) knowledge of the treatment team members would complement their knowledge of services that may be necessary. This would allow the caregiver, who knows the individual diagnosed with a brain injury best, and the team to advocate for access to services when needed in order to address many of the needs of the individual diagnosed with a brain injury.

Need for a Traumatic Brain Injury Handbook

Based upon a review of the literature it was found that information is needed for caregiver(s) and family of an individual who has experienced a TBI. A handbook was developed to fill the gaps found in the literature and is based upon current research,
literature, and best practices. Based on current literature outcomes for the individual diagnosed with a brain injury are poorer when the caregiver/family member is not educated or involved in the treatment process. Radomski (2002) illustrates this point effectively by stating:

Patients’ families continue to require information and support to understand the recovery and rehabilitation process and to inform their decision making and discharge planning. . . recommended that the rehabilitation team provide the family with information about the following topics: (1) the full spectrum of possible TBI outcomes to enhance realistic expectations; (2) the effects of TBI on family systems and possible alterations in family dynamics post discharge; (3) the benefits, challenges, and responsibilities of caretaking and supervision post discharge; (4) resources available for postacute rehabilitation. (p. 874)

The Traumatic Brain Injury: Caregiver and Family Education Handbook integrates the information found in the literature review using the Occupational Adaptation Theoretical Frame of Reference. The goal is to help the caregiver/family member(s) adapt to their new role in the life of the individual diagnosed with a traumatic brain injury. They are guided in the adaptation process by providing education about brain injury and introduced to occupational therapy interventions that can be carried over into the home. This information is designed to help the caregiver/family member achieve relative mastery in their caretaking role and produce better outcomes for the individual diagnosed with a brain injury.

The outcome of the scholarly project is a tool for practicing Occupational Therapists (OT) to provide to the family member(s) and caregiver(s) of individuals diagnosed with a TBI. This will benefit the individual diagnosed with a brain injury by having activities that carry over the intervention provided by the OT in the clinic and allow the family to become more involved in understanding and meeting the needs of the
individual diagnosed with a brain injury. The information is based on current evidence based literature and current best practice methods. The information compiled will allow the family member(s) and caretakers to be educated and empower them to feel as though they are participating members in the individual diagnosed with a brain injury's recovery process. The information was organized as follows: (1) a review of definitions related to TBI, (2) the findings regarding expectations of function following injury, (3) the need for a broad range of interventions and approaches for best outcomes including social and emotional needs of the caregiver and injured individual, (4) the impact on the family and caregiver(s), and (5) services offered for rehabilitation.
CHAPTER III
ACTIVITIES/METHODOLOGY

The product is a handbook for caregiver(s) of individuals with Traumatic Brain Injury (TBI). The methodology used to gather information for the development of the caregiver handbook included a review of the current literature and research on Traumatic Brain Injury and discussions with therapists who are currently treating patients with TBI.

The product is based upon many suggestions from professionals and information in the literature suggesting that: (1) it is difficult to care for and individual with a TBI; (2) that the lack of education usually leads to cessation of therapy or seeking therapy beyond an acceptable time frame; (3) that caregiver(s) have high stress and low satisfaction; (4) caregiver(s) lack of understanding of TBI leads to unrealistic expectations of the brain injured individual; and (5) caregiver(s) do not utilize resources and treatment methods that are available because they are unaware of their existence or benefits. The handbook is intended to decrease incidence of these issues and result in best possible outcomes for the individual diagnosed with a traumatic brain injury.

These issues were addressed through the application of the Occupational Adaptation Theory. This theory was chosen because it allowed the information found in the literature review to be integrated to address the areas of concern, allowing the
caregiver(s)/family member(s) to achieve relative mastery by adapting successfully to their new role.

The product is a guide for caregiver(s) of individuals with Traumatic Brain Injury (TBI). The methodology used to gather information for the development of the caregiver guide included a review of the current literature and research on Traumatic Brain Injury and discussions with therapists who are currently treating patients with TBI.
CHAPTER IV

PRODUCT

The development of the Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook was based on the literature addressing Traumatic Brain Injury (TBI) recovery and issues for caregiver(s) and family member(s). Radomski (2002) states:

Patients’ families continue to require information and support to understand the recovery and rehabilitation process and to inform their decision making and discharge planning. . . recommended that the rehabilitation team provide the family with information about the following topics: (1) the full spectrum of possible TBI outcomes to enhance realistic expectations; (2) the effects of TBI on family systems and possible alterations in family dynamics post discharge, (the benefits, challenges, and responsibilities of caretaking and supervision post discharge; (4) resources available for postacute rehabilitation. (p. 874)

The Traumatic Brain Injury (TBI): Caregiver and Family Education Handbook contains information that will educate caregiver(s)/family member(s) about traumatic brain injury and the rehabilitation process and allow them to become active members of the treatment team by providing examples of activities they may encounter in therapy and examples of those that can be integrated in the home environment. The handbook includes: terminology, an introduction to the treatment team, generalized TBI information, areas of concern, differences to expect in the individual diagnosed with a brain injury, occupational therapy rehabilitation, family support and self reflection.
Traumatic Brain Injury (TBI):
Caregiver and Family Education Handbook

Heather Yekel, MOTS
Breana Medlock, MOTS
University of North Dakota
Casper College
Occupational Therapy
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Introduction

Traumatic brain injury (TBI) can be devastating for the person you love as well as the entire family. You probably have many questions about the injury and what is to be expected for your loved one's life.

This handbook was designed to answer as many of the questions you may have at a difficult and confusing time. We have taken the current research information on traumatic brain injury and incorporated it into this handbook. The information in this guide is focused on areas of concern for you and your loved ones with a focus on the role of occupational therapy intervention/treatment.

This handbook contains information that we hope will help you understand traumatic brain injury and the process in recovery. The information in this handbook includes:

1. Definitions of traumatic brain injury and related terms
2. An introduction to the medical treatment team members
3. Basic information about traumatic brain injury
4. Common areas of concern in TBI recovery
5. What differences to expect in the individual diagnosed with a brain injury
6. Occupational therapy rehabilitation
7. Family support and resources

8. Self reflection
Definitions of Traumatic Brain Injury and Related Terms

The following definitions were adapted from Gutman (2001), Radomski (2002), and other sources which are provided for you in the end of this handbook in the reference section. These terms have been adapted to avoid medical jargon.

**TBI:** An injury to the brain usually resulting from a head injury. This injury may cause altered states of consciousness and impairment of thinking, behavior, emotions, and physical functioning.

**Blunt Trauma:** The most common cause of TBI and is frequently the result of motor vehicle accidents and bicycle crashes, pedestrian vs. auto impacts, falls, sports, and assaults. This is an injury caused by a blow to the head.

**Penetrating TBI:** Can be the result of any sharp or blunt object entering into the brain.

**Blast:** When an injury has caused damage by a blow to the head and an object entering the brain.

**Open Head Injury:** Injury in which the skull is fractured or penetrated.

**Closed Head Injury:** Injury in which the skull remains intact.
**TBI as Primary Injury:** Occurs as a result of the initial impact to the head, damaging brain tissues. Can be classified as focal or diffuse.

**Focal Injury:** Commonly caused by penetrating wounds and is often the result of an open head injury. Called focal because the damage is in the location of the object which has entered the brain.

**Contusion:** May be caused by a skull fracture or shaking of the brain back and forth within the skull. This causes bruising of brain tissues when the injured area swells and blood is released from broken blood vessels. This type of injury is called contrecoup.

**Diffuse Injury:** This means there is damage throughout the brain, or not in one specific location. These injuries, termed diffuse axonal injuries, result in coma.

- **TBI Secondary Injury:** Damage to the brain caused by other body functions. For example: if another bodily injury occurred, such as a vessel in the brain breaking causing damage that would not allow the brain to function.

**Glasgow Coma Scale (GCS):** A scale used by doctors to determine the category of the brain injury (mild, moderate, severe). This scale generates a score between 3 and 15 based on a person’s abilities in eye opening, and motor (movement of body) and
verbal (speaking) function. For each of the categories (eye opening, best motor response, and verbal response) a score is given according to the individual diagnosed with a brain injury's behaviors. The score is totaled and it is used to categorize individual diagnosed with a brain injury into mild, moderate, or severe brain injury categories.

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Table 1: Glasgow Coma Scale  {Adapted from Radomski (2002, p. 859)}

**Mild TBI:** Glasgow Coma Scale Score of 13 to 15. A person in the mild TBI category will have at least one of the following: any period of loss of consciousness, any loss of memory for events
immediately before or after the accident, any alteration in mental state at the time of the accident, focal neurological deficit (brain injury affecting one ability such as sight or speech).

**Moderate TBI:** Initial Glasgow Coma Scale score of 9 to 12; post traumatic amnesia (loss of memory following the incident) of 1 to 24 hours.

**Severe TBI:** Loss of consciousness longer than 6 hours; initial Glasgow Coma Scale score of 8 or less.

**Post Traumatic Amnesia:** The period of time following an injury in which the brain is unable to lay down continuous day to day memory.

**Concussion:** Concussion is a temporary brain dysfunction as a result of a force applied to the brain. Concussions may be mild or moderate.

**Mild Concussion:** Results in temporary brain dysfunction without any loss of consciousness or loss of memory.

**Moderate Concussion:** Also called classic concussion, usually results in the same deficits seen in mild concussion, as well as unconsciousness and memory loss. Recovery from moderate concussion can take minutes, to hours, to days.

**Post-Concussion Syndrome:** Includes symptoms such as irritability, fatigue (feeling tired), headache, difficulty concentrating,
dizziness, and memory problems. These problems may arise days or months to even years after the initial injury. This syndrome often leads to inability to sleep, anxiety, and depression.

**Post Traumatic Stress Disorder:** PTSD is a reaction to seeing, hearing, or being involved in a traumatic experience. The person reacts to this experience with fear and helplessness, persistently relives the event and tries to avoid being reminded of it.

**Orientation:** awareness of time, place, and person. This means the individual can identify where they are; what time of day, year, and month it is; and who they and other important people are.

**Acute Phase:** This consists of the time frame between the gurney to the Intensive Care Unit (ICU). This stage usually lasts hours. Diagnosis and assessment occur at this time. (Radomski, 2002)

**Pre-Injury Phase:** All time of life before the injury and includes the individuals experiences, skills, abilities, personality and attributes. (Radomski, 2002)

**Medical Treatment:** Includes the acute phase which consists of the gurney to the intensive care unit (ICU) where diagnosis is made and treatment begins, and the intensive phase where the
individual is in the ICU to an acute hospital discharge where diagnosis and treatment are ongoing. (Radomski, 2002)

**Rehabilitation or Recovery Stage:** Consists of education and training and conditioning. This could last for months or years where assessment of abilities and deficits and training is ongoing. (Radomski, 2002)

**Survivorship Stage:** Stage where the individual attempts to establish and live a new life. Personal, social, and quality of life adjustments are made. (Radomski, 2002)

**Cervical Pain:** Neck Pain

**Vestibular System:** Within the inner ear, problems with the vestibular system can lead to dizziness.

**Insomnia:** Chronic inability to sleep.

**Interpersonal Relationships:** Relationships with other people.

**Sub-Acute:** Between acute and chronic phases of a disease.

**Post-Acute:** After the acute phase.

**Chronic:** Marked by a long duration or frequent occurrence.

**Verbally Combative:** To be verbally (through speech) abusive or argumentative.

**Physically Combative:** To be physically (with the body) abusive.

**Social Inappropriateness:** Acting or verbalizing in a way that is socially inappropriate (not accepted within social norms).
**Disinhibition:** Loss or reduction of an inhibition caused by interfering stimuli or events. One is aware of the difference between right and wrong but does not have the personal control to keep from performing an act considered "wrong".

**Impulsivity:** Acting momentarily, not thinking before doing.

**Neurological Damage:** Damage to neurons.

**Neurons:** Components of the nervous system. These conduct messages for the body to carry out activities.

**Cognition:** The act or process of knowing including both awareness and judgment.

**Short Term Memory:** This is the working memory, it store the information you need to remember in the following seconds, minutes, or hours.

**Long Term Memory:** Stores information that your brain retains from short term memory.

**Deductive Reasoning:** The ability to use available information to make logical assumptions.

**Categorization:** The ability to place objects into categories such as circles or red.

**Concrete Thinking:** Inability to think in abstract terms and will give an over-literal interpretation of proverbs, for example when asked
about the phrase “a rolling stone gathers no moss” the explanation revolves around stones and moss.

**Abstract Concepts:** Thinking characterized by the ability to use concepts and to make and understand generalizations, such as of the properties or pattern shared by a variety of specific items or events.

**Sequencing:** Ability to complete a thought or task in a logical beginning to end order.

**Visual Processing:** Processing that occurs in the brain of visual images.

**Figure Ground Discrimination:** Ability to determine what is near and what is far.

**Assistive Technology:** Equipment prescribed to help accomplish a task that can no longer be completed due to injury.

**Pre-Vocational Therapy:** Focuses on individual and cognitive abilities to find out what job the person is physically and mentally capable of doing.

**Vocation:** A regular profession (job), one for which an individual is suited or qualified.
Four Phases of the TBI Survivor

Pretrauma Phase
Duration: variable (prenatal to decades)
Personality, education, skills, personal history

Preinjury

Acute Phase: Gurney to intensive care unit (ICU)
Duration: Hours
Diagnosis/triage, treatment(s)

Medical Treatment

Intensive Phase: ICU to acute hospital discharge
Duration: days/weeks
Diagnosis/treatment(s)

Rehabilitation

Recovery Phase: Education and training/conditioning
Duration: months/years
Assessment of abilities and deficits, training program(s)

Survivorship

Survival Phase: establishing and living a new life
Duration: decades/lifetime
Personal adjustment (abilities, deficits, personality, etc)
Social Adjustment (family, friends, work, peers, etc)
Quality of Life (productive, happy, engaged, etc)

Figure 1: Four Phases of life of the TBI Survivor Radomski (2002, p. 858)
This chart provides an illustration that allows caregiver(s), family member(s), and the individual diagnosed with a brain injury to see the phases of survivorship. This may help them to understand what they have experienced and what they have to look forward to.
Introduction to Medical Treatment Team

The treatment team is comprised of the professionals who are helping the individual diagnosed with a brain injury, the person diagnosed with the brain injury, and the caregiver(s) and family member(s). It is important that all treatment team members be active and informed to accomplish one main goal: The best possible outcome for the individual diagnosed with a brain injury.

Here is a list of possible treatment team members, and what their job description is so you may utilize them to the best advantage of the individual diagnosed with a brain injury.

**Occupational Therapist (OT):** The occupational therapist will be working with the individual diagnosed with a brain injury on a regular schedule so they may return to all occupations of life. Occupational therapists will follow the individual diagnosed with a brain injury from their very acute stages to the survivorship stages. The occupational therapist’s role in recovery is to assist the individual diagnosed with a brain injury to participate in basic daily life functions such as toileting and bathing at first, then to participate in more complex activities that they will need to do on a daily basis such as cooking and managing money.
**Physical Therapist (PT):** The PT will work on gross motor (large muscle) movements in the body. This means they will be working on the arms, legs, and trunk for long coordinated movements such as walking or swinging your arms. You should address any concerns with balance, gross motor abilities (large muscle movements), and gait (walking) with the PT.

**Speech Language Pathologist (SLP):** "A specialist who evaluates and treats communication disorders and swallowing problems. A speech-language pathologist is sometimes called a speech therapist or speech pathologist" (Medicinenet.com). This professional will assist with any concerns with eating, swallowing, and speaking.

**Vocational Counselor (VC):** assist people with disabilities to plan careers as well as to find and keep jobs.

**Physician (MD):** A physician is referred to as a doctor of medicine. The doctor will diagnose and prescribe treatment. This person is often referred to as a general practitioner and should be consulted for all non brain injury related medical issues.

**Neurologist (MD Neurology):** A doctor of medicine who specializes in diagnosis and treatment of disorders of the nervous system including brain and spinal cord. The neurologist should be consulted for all brain injury related issues.
**Social Worker:** The social worker is the contact between the individual diagnosed with a brain injury and the medical staff. They use their medical knowledge to advocate for the individual diagnosed with a brain injury. The social worker will help the individual diagnosed with a brain injury and their families obtain necessary resources. For example: if you live in a rural area and accessing necessary rehabilitative services are difficult you would contact the social worker to find out if any in home services, or who would be the closest therapy provider.

**Case Manager:** “A case manager is a health care professional, who is employed to manage and coordinate complex medical cases to ensure quality and efficient use of health care resources” (American Academy of Family Physicians). The case manager can be anyone on the team, but it is usually the social worker who takes on this role.

**Nurse:** A person trained, licensed, or skilled in nursing. The nurse can answer your general questions about health care, diagnoses, etc.

**Psychiatrist:** “A physician (an M.D.) who specializes in the prevention, diagnosis, and treatment of mental illness. They can prescribe medication, which psychologists cannot do” (Medicinenet.com). The psychiatrist may be helpful to consult for emotional or behavioral concerns.
Psychologist: “A professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems. Psychologists can only use talk therapy as treatment; you must see a psychiatrist or other medical doctor to be treated with medication.” (Medicinenet.com). The psychologist may also be helpful to consult for emotional or behavioral concerns.

Caregiver: This is the person offering the direct care to the individual diagnosed with the brain injury. The individual diagnosed with a brain injury may be living at home and the caregiver(s) will be the family member(s) who are responsible for their well being. The caregiver(s) have valuable information to give because they are the ones that spend the most time with the individual with the brain injury. The caregiver should share their knowledge with the rest of the team to make sure everyone is up to date on the progress or any setbacks with the individual diagnosed with a brain injury.

Family: The relatives of the individual with the brain injury. The family should prepare for their relationship with the individual with the brain injury to be different. Taking care of an individual with a brain injury may put strain on the family unit. The family should support each other while taking care of the individual diagnosed with a brain injury.
Individual diagnosed with a brain injury: This individual is at the center of the treatment team and should be involved with all decisions possible. This individual will experience many changes physically, cognitively, and emotionally.
Brain injury is a very common injury. This section will tell just how common the injury is and give statistics and information relating to brain injury.

- "Each year approximately 373,000 Americans are hospitalized as a result of TBI" (Gutman, 2002, p. 672).
- Nolan (2005) states that 5.3 million individuals are currently living with various disabilities related to TBI.

This disorder is most common among males. It is commonly believed that this is due to the risk taking behaviors of young men. Most young men obtain a TBI as a direct result of motor vehicle accidents, violence, and sports. Alcohol use is also a contributor to TBI incidence. TBI is also prevalent among infants, toddlers, and elderly.

It is estimated that 99,000 of the individuals who obtain a TBI will have moderate to severe injuries resulting in life long disability. Statistics also show that of those who experience a TBI 15-20% will sustain a second TBI. This is why it is important to take part in appropriate rehabilitative treatment that includes cognitive, perceptual, psychosocial and physical treatments.


Common Areas of Concern in TBI Recovery

When a person experiences a traumatic brain injury their life is changed because their ability to function has changed. Research has found that the most common areas of concern directly after a TBI are: cost, time for recovery, return to work, return to school, return to driving, and treatment expectations.

Cost

Annual cost of TBI was estimated to be 48.3 billion (for all injuries, not one isolated event). “The average lifetime cost per survivor of TBI requiring hospitalization was $111,578” (Brener, Harman, Kelleher, & Yeates, 2004, p. 405). The majority of the cost is attributed to post-acute hospitalization and supported living arrangements for those who require life long rehabilitation assistance.

Recovery Time Frame

The time frame of recovery is variable. Due to the wide range of injuries that could occur and symptoms that present there is no specific time frame for recovery available. Studies of recovery show ongoing improvements for a period of 2-5 years after the injury (Khan, Baguley, & Cameron, 2003).
Return to Work

The individual diagnosed with a brain injury may be able to work in a position that is suited to their skill set, however the individual may not be able to return to their previous level of ability and therefore will not return to their previous employment. After brain injury an individual must have the physical and cognitive ability to return to work. The individual must have the ability to process the information to complete the work task in a safe and productive manner. The individual’s skill set must match the demands of the job. With brain injury there are a wide variety of deficits such as decreased attention, irritability, and fatigue, which may prevent them from being successful in the workplace. The individual diagnosed with a brain injury may be able to work in a position that is suited to their skill set, however the individual may not be able to return to their previous level of ability and therefore will not return to their previous employment.

If it is the goal of the individual diagnosed with a brain injury to return to work there are programs to help them with that goal. Programs aimed at return to work will focus on work behaviors and habits such as punctuality, thoroughness, response to feedback, and ability to take and use notes (depending on the vocation). Individuals with TBI may first try volunteer jobs to employ compensatory cognitive strategies and build their endurance and work tolerance.
Examples of appropriate placements for the skills and abilities of the individual diagnosed with a brain injury are industrial jobs or assembly lines. Individuals with brain injuries have found success in industrial positions because of the consistent routine, repetitive tasks, and necessity of concrete thinking. These jobs do not have high demand for interpersonal skills, problem solving, or cognitive flexibility.

Return to School

Return to school is similar to return to work, it is an occupation that may consume much of the time of the individual diagnosed with a brain injury. The student may have cognitive deficits hindering academic ability. Modifications and related educational services may be necessary for success in the school setting.

Hawley, Ward, Magnay, & Mychalkiw (2004) explain the necessity of including the school in the team approach of rehabilitation. Schools rely on the parents (caregiver(s)) of the individual diagnosed with a brain injury to inform them of any deficits and needs. At hospital discharge, health professionals should provide the schools with information about TBI so that children returning to school receive necessary supports. The social worker/case manager
may also be helpful in coordinating school related services so your child may be successful in school.

_Return to Driving_

Due to cognitive impairments, driving a motor vehicle can be a difficult task. Driving is a task that most adults are required to do in their daily lives for survival. After suffering a TBI the individual is often curious about returning to this vital task.

"Many states require physicians to report to the Department of Motor Vehicles any individual diagnosed with a brain injury who has lapses of consciousness, seizure disorders, and cognitive, visual and perceptual dysfunction caused by TBI” (Gutman, 2001, p. 691). Regulations surrounding TBI often mean the driver’s license will be revoked until assessment confirms that the patient is not posing a safety risk to self or others while driving. (Gutman, 2001) Occupational therapists can provide the proper assessment and training with modifications as needed.

_Treatment Expectations_

There are many factors dictating which services the brain injured individual will receive including: nature of the survivor’s insurance, service availability in the local area, patient and family preferences,
injury severity, and local care practices. Also instrumental in services provided is the current trend in healthcare to reduce costs from Medicare and managed care organizations leading to shorter hospital stays (Phillips, Greenspan, Stringer, Stroble, & Lehtonen, 2004).

Each injury and individual is unique, meaning each treatment approach should be client specific. Treatment should meet all needs of the individual diagnosed with a brain injury for best outcomes. If you feel a treatment is necessary that the individual diagnosed with a brain injury is not receiving, or that they are receiving a treatment they do not need you should discuss the issue with the treatment team.
Differences to Expect in the Individual Diagnosed With Brain Injury

The individual diagnosed with brain injury will not act the same or think the same depending on how they were affected by the injury. Because behavior, social participation, and cognitive ability are all areas addressed by occupational therapy we thought it may be useful for you to understand a little bit about how these deficits can affect the individual diagnosed with brain injury's ability to function.

Behavioral and Social Effects

Usually the unexpected results for an individual who has experienced a head trauma are the behavioral and social deficits. Gutman (2001), states that agitation is common and may cause safety issues or interfere with the rehabilitation process. Persons with a brain injury may become verbally or physically combative; act mildly confused and agitated; or severely confused, impatient, and irritated. These behavioral disturbances are organically based and result from specific brain damage. Behavioral disturbances are common in TBI recovery, and it is important for the caregiver(s) to not take any aggressive acts by the individual diagnosed with a brain injury personally. It may also be helpful for the caregiver(s) to explain to others who interact with the individual diagnosed with a brain injury...
that the aggressive behavior and change in personality may be side effects of the brain injury.

Social roles are a large contributor to self-image. When a person experiences a brain injury they lose most of their social roles and the activities that used to support those roles. Social inappropriateness and disinhibition are common behavioral problems. The social inappropriateness may include using obscenities, making sexual advances, and removing clothing in public (Khan et al., 2003).

Caregiver(s) may be curious as to when this behavior will stop. Individuals diagnosed with a brain injury experience agitation and confusion for weeks or even months. These behaviors may be replaced with more appropriate actions as the brain recovers. Some brain injuries result in severe behavioral disturbances that do not change with time.

_Cognitive Deficits_

The changes in the thought process caused by brain injury will affect the individual diagnosed with a brain injury’s ability to make choices in every day tasks. TBI can affect competency to make important financial decisions, comply with medical management, give informed consent, and make other life decisions. (Khan et al., 2003)
Everyday tasks such as brushing teeth and combing hair require higher level functioning skills such as deductive reasoning and categorization skills (Goverover and Hinojosa, 2002).

A person experiencing a brain injury often results in having concrete thinking. Abstract concepts and generalization of ideas and skills from one task to another may be difficult. For example an individual may be able to brush their hair but not brush their teeth. (Gutman, 2001) In order to work on every day tasks their mental abilities may need to be refined.
Occupational Therapy Rehabilitation

Occupational therapy is necessary for rehabilitation of TBI. Occupations can include very basic activities such as combing your hair and showering, to very difficult activities such as navigating a store within the community and shopping for groceries.

Occupational therapy is designed to address ability to function. Occupational therapy provides multiple interventions to address physical, cognitive, emotional, and social needs of the individual diagnosed with a brain injury. If ability to function in these areas is affected it can have a devastating affect on the way you function in other areas of life.

You should inform the OT if you have any concerns with the individual diagnosed with a brain injury’s ability to function or perform everyday tasks. The Occupational Therapist will use that information to build a treatment plan to address your concerns as well as the concerns of the individual who is diagnosed with brain injury.

Preparatory Occupational Therapy Intervention

The OT usually begins the rehabilitation process with preparatory interventions because you have to have the basic abilities before you can accomplish any task. These activities will vary depending on the goals the individual diagnosed with a brain injury is working on. The
Occupational Therapist will explain what they are doing, and why they are doing it. Just keep in mind the “you have to crawl before you can walk” concept because sometimes the activities the therapist is completing with the individual diagnosed with the brain injury may not seem relevant to their overall goals. The Occupational Therapist may involve you in the treatment process and would appreciate input at any time. The therapist will inform you of ways you can help the individual diagnosed with a brain injury to increase their functioning in everyday tasks.

Examples of tasks that the therapist may request include: using verbal and visual cues within the home, adapting the home environment for easier access, integrating routines, completing memory activities, cognitive retraining activities, stress and anger management activities, and being involved with social participation and community activities.

**Specific Interventions**

The occupational therapy interventions will be explained so you have a better understanding of how they will address the functional issues of the individual who has a brain injury.

Treatment may include social participation and community integration. Considering the importance of social integration and social rehabilitation after TBI, social integration is included in many
rehabilitation programs. A small number of studies suggest that social rehabilitation can produce improvements in participation and community integration. Rehabilitation may exert its benefits not only by facilitating improvements, but also by preventing declines in community functioning (Cicerone, 2004).

Environmental adaptation is rearranging or changing the environment to best fit the needs of the injured individual. Research has found that environmental barriers affect level of participation. If you find that the individual diagnosed with a brain injury is not thriving in their environment ask your occupational therapist how they can help. For example confusion and agitation often occur with TBI. To reduce confusion the therapist may suggest that you keep the environments most common for the individual diagnosed with a brain injury very structured and simplistic. By keeping the environment the same and reducing the amount of objects to interact with, the individual may become less confused and agitated.

Use of verbal and environmental cues can address the issues of sequencing and memory so the individual diagnosed with a brain injury can complete tasks. The kitchen task can be adapted with a verbal or visual cue (sign) to turn off the stove when the cooking task is complete. A home maintenance task such as making the bed may require a verbal cue to initiate, then the task is adapted by using a
sign above the bed listing the steps and appropriate time to complete the task. The occupational therapist will instruct you if it is necessary to provide verbal cues.

Sequencing tasks are learned through simple step by step projects such as putting together a story board or following four step directions. The occupational therapist may work on sequencing by giving the individual diagnosed with a brain injury short craft projects or recipes with simple directions. These activities can be completed in the home and the therapist may suggest that you provide opportunities to complete these tasks.

Memory deficits may require long periods of time for rehabilitation. For individuals with severe memory deficits a memory journal may be helpful. A memory journal is in a day planner format. Appointments can be written in the memory journal and entries of what activities were participated in throughout the day. The occupational therapist will assist in setting up the journal and educating on it's uses. The memory journal works best when it is read and written in regularly. It is a reminder of what the individual diagnosed with a brain injury has done, and what they need to do in the future. This may assist them in building routines and remembering important events. The occupational therapist will require your assistance to make sure the journal is being used habitually. You
may be required to provide verbal cues to write in or refer to the memory journal.

In conjunction with or instead of the memory journal other devices may be used as reminders. High tech devices such as PDA's (personal digital assistants) have alarms, task lists, and an area to catalog memos. These devices will also require your assistance to be used in an effective way.

Another intervention for cognitive impairment is computer assisted cognitive retraining (CACR). CACR has been used as an effective addition to traditional rehabilitation techniques. CACR is derived from three sources: video games, educational software, and specially written cognitive rehabilitation programs. The goal of CACR is to regain skills through use of computer programs. The occupational therapist may suggest these programs be used in the home. Your assistance will be required to give verbal cues for initiation and monitoring of these tasks.

It may be necessary to provide a behavioral management program for individuals diagnosed with a brain injury. If this is necessary the occupational therapist will help develop a program that will fit the specific behavior management needs. The program will need to be implemented in the home by the caregiver(s).
Family Support

Caring for an individual with a TBI can be a great responsibility requiring hard work. It is common for caregiver(s) to feel alone and become overwhelmed. Research has found that caregiver(s) are at risk for depression, anxiety, and high levels of stress. There may be a need for additional support for the caregiver(s) to cope with adapting to their new role as a caregiver.

It is important to find ways to balance your life and meet your needs when adapting to the role of the caregiver. Taking care of an individual with a brain injury is considered to be work, and in doing so it may be easy to let other important things in your life go unattended. Eventually you may find there is no time for yourself and your stress level will be elevated. Finding a way to balance the new routine with the old routine may be difficult, but not impossible. This is common and there is help to reduce stressors. There are support groups, respite care, counselors, psychologists, and possibly other family member(s) to help with the emotional strain.

Respite Care

Respite care is a health care service where health care workers come to stay with and take care of the individual diagnosed with a brain injury. Some respite care providers will have the individual
diagnosed with a brain injury come to their home or facility. The goal of respite care is to give the family and caregiver(s) a rest or break. Respite care can be provided when the caregiver or family member(s) require time without the individual diagnosed with a brain injury.

Support and Information Groups

There are many support groups and information sources for you and for the individual diagnosed with the brain injury. Support groups are a great way to interact with others who may be experiencing the same situation. The other members of the support group may be able to give you tips or information that would be helpful in the process of caring for an individual diagnosed with a brain injury.

- **TBIhelp.org** -- Help for TBI Caregiver(s) -- Presented By Jamaica Hospital Medical Center -- Sponsored By United Hospital Fund. **Featuring:** Live professionally moderated chat: Mondays - 7 to 8pm (EST) - **url:** http://www.TBIhelp.org/

- **Care-giver.com** -- Resourses and information for caregivers. **url:** http://www.care-giver.com/

- **Empowering Caregivers**-- Resourses and information for caregivers. **url:** http://www.care-givers.com

- **Family Caregiver Alliance** - offers online information and support to families of persons with traumatic brain injury. **url:** http://www.caregiver.org
• **National Family Caregivers Association** NFCA -- 10400 Connecticut Avenue, Ste 500, Kensington, MD 20895-3944 -- Dedicated to making life better for America's family caregivers.

  **Telephone:** 301-942-6430;
  **Toll Free:** 800-896-3650; **Fax:** 301-942-2302 -
  **url:** http://www.nfcacares.org -
  **email:** jeannie@nfcacares.org

• **National Fathers Network** -- An excellent site pertaining to kids, teenagers and adults.  **url:** http://www.fathersnetwork.org/

• **Orange Caregiver Resource Center** -- **Telephone:** 714-578-8670 **Toll Free:** 800-543-8312  **url:** http://www.caregiveroc.org

• **No Tears In Heaven** -- Est. in 2000 following their 12 year old son's anoxic brain injury due to cardiac arrest  
  **url:**http://www.notearsinheaven.com/

• **Brain Injury Society** - Brooklyn, NY 11230 **Telephone:** 718-645-4401--Referrals, consumer and legal advocacy, and support groups. NYS Medicaid Waiver Provider Services, educational forums, and decision support.  **url:** http://www.bisociety.org

• **Brain Injury Support Group of Portland** - 2145 NE Overton, Portland, OR 97210 -- **Telephone:** 503-413-7707;  
  **email:** headsup@pacifier.com
• Cafe Plus: 216 W. Manlius St., E. Syracuse, N.Y., Telephone: 315-446-3124 - A social group for people who have survived head injury. Meets every Sat. 12 to 4, p.m., est. Refreshments, Companionship and much more!
  url: http://www.dreamscape.com/cafeplus/
  email: cafeplus@dreamscape.com

• Head Injury Hotline: A non profit clearinghouse founded and operated by head injury survivors since 1985. It is a place where visitors can get information, join a discussion group, build advocacy skills, and self-care skills. The site integrates resources from diverse organizations including support groups, rehabilitation, and research sites, as well as lay and professional journals and more. email: brain@headinjury.com

  email: icepots@peoplepc.com

• TPN Inc., The Perspectives Network - PO Box 1859, Cumming GA 30028-1859 - Voice/Fax: 770-844-6898 -- Provides forums and resources for persons with brain injury, their families, caregivers, friends and the professionals who
serve them. Their goals are to promote a sense of community, and to increase public awareness of brain injury. **url:**

http://www.tbi.org -- **email:** TPN@tbi.org

- **Traumatic Brain Injury** - Dedicated to survivors and all who wish to learn more about traumatic brain injury. **url:**

http://bjscloset.org/

- **Respite Care Resource:**

http://www.acponline.org/public/h_care/6-respit.htm
Self Reflection

As the caregiver of the individual diagnosed with a brain injury there are many new tasks and barriers to overcome. You are learning about the injuries, how the injuries affect the individual, and how to adapt to living with the changes that have occurred. This is not an easy task, and to prevent “burn out” you will want to take time to reflect on what you have learned, what techniques related to working with the individual diagnosed with a brain injury are working for you, what is not working, and what you think will work better.

The occupational therapist may monitor your progress as well as the individual diagnosed with a brain injury and encourage you to keep a journal. A journal is an excellent way to record your experience. This journal can help to: record the experience of taking care of the individual diagnosed with a brain injury; express feelings or emotions; provide insight to what is and what is not working (with caregiving); monitor for “burn-out”; discover need for additional services (for the individual diagnosed with a brain injury or the caregiver). Included is a chart that will help to guide your reflections. Journaling should be done at least weekly.
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<th>What happened today?</th>
<th>How are you feeling?</th>
<th>How was the reaction of the individual?</th>
<th>What is working well?</th>
<th>Could something be done differently?</th>
<th>Is there a need for additional services?</th>
<th>Questions for the care team?</th>
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**Figure 2: Self Reflection Guide**
Summary

This handbook was meant to be a guide to increase your understanding and participation in this long life journey. Use the suggestions to empower yourself to participate. Remember to monitor your own feelings and emotions and seek help if you need it. Don’t be discouraged, but don’t be afraid if you are (it’s not an easy adjustment).
References


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CHAPTER V
SUMMARY

According to Gutman (2002) and Nolan (2005) there are currently 5.3 million individuals living with disabilities related to a TBI and 373,000 incidences of traumatic brain injuries each year. This handbook was designed to guide the family member(s) and caretakers of these individual diagnosed with a brain injury’s. It is recommended that Occupational Therapists use this manual as a supplemental guide to educate caretakers and family member(s). Therapists who distribute this manual should document the effectiveness of having a manual for additional caregiver and parent education.

Scholarly Project Limitations

1) This project was limited by the broad range of effects at TBI can have. The original intent was to include exercises that could be done at home, but considering that a TBI is not a “one size fits all” disorder there are few interventions that would be completed with all brain injured individuals.

2) The Occupational Therapy (OT) students found in the review of the literature there is not an abundance of evidence based research on various interventions for TBI.

3) Throughout the process of the literature review and production of the product the OT students found there were areas that could have been further investigated such as the long term effects of Post Traumatic Stress Disorder,
4) depression, and symptomology. However, the OT students felt it was not
critical to the production of the product.

5) The research is also lacking in return to post-elementary and collegiate level
education for individuals with a brain injury. Research regarding generalized
activities that are best suited for each brain injury category (mild, moderate,
severe) would have helped the product as well.

In conclusion the product is based off of the most current literature and aimed not
only to help the brain injured individual to reach the best possible outcome, but to help
the caregiver and family member(s) to cope with the drastic changes.
REFERENCES


