AN ABSTRACT OF THE THESIS OF

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Traumatic brain injury (TBI) is a leading cause of death and disability in the United States. However, along with the increase in the occurrence of TBI, there has been a drastic decrease in the acute and long-term care provided for the TBI patient. This study provides information on the short- and long-term effects of TBI, current therapeutic methods used to treat TBI, and an analysis of the efficacy of those methods based on primary patient accounts of their experiences in therapy. Specific questions were asked of patient respondents about their injury, opinions of the rehabilitation received, and current quality of life using a qualitative online questionnaire compiled by this author and advisor. Results describe that current therapy regimens are too brief, brain injury is frequently misunderstood by healthcare providers, and brain injury should not be managed as an acute event but rather an extensive and most often lifelong process. A synopsis of the effects of brain injury and current healing modalities using established clinical research and survey results is offered. Suggestions are made about the future direction of treating and rehabilitating patients with TBI based upon those findings, this author’s personal experience with TBI, and patient pathographies.

Keywords: head, brain, trauma, treatment, recovery, disability, therapy, survey

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Traumatic Brain Injury: Associated Psychological Consequences
and Effectiveness of Therapies

by

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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Jessica C. Hansen, author
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I would like to thank all members of my thesis committee for their influence on my education and personal growth during my time at Oregon State University. From them my passion for medicine and learning grew and now encompasses a thorough understanding of the science and humanistic aspects behind healthcare and where my own pursuits lie within the field.

I also thank my parents, Dave and Debbie Hansen, for their unending support in all aspects of my life. My father and mother have been the soil from which all things in my life have grown. Without what they have given me I surely would not be the person I am today.
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PERSONAL INTRODUCTION AND DEDICATION

According to the Centers for Disease Control and Prevention, approximately 1.7 million people sustain a traumatic brain injury (TBI) each year, of which 52,000 die, 275,000 are hospitalized, and 1.325 million are treated and released from an emergency department (CDC “Statistics”). Even though the occurrence of TBI is quickly rising, awareness of the seriousness of TBI and prevention methods falls far short of what is needed to contain this growing epidemic.

Awareness of TBI is on the rise, though ask any person affected by TBI and they will tell you awareness is not rising fast enough, this epidemic must be stopped. Now billboards sponsored by state departments of transportation are posted urging drivers to slow down, showing a photograph of a speeding skull with the caption “Dying to get there.” I myself was one day ‘dying to get there’ and driving unreasonably fast, approximately 90 miles per hour on a windy two-lane mountain highway. I was late, and I was invincible. I lost control of my car when I steered right to avoid hitting another vehicle and rocketed off the road. After crashing through underbrush and small trees, I abruptly collided with a tall and deeply rooted fir tree. In the first few seconds after the collision I was conscious, I distinctly remember mentally checking my body for broken bones and running my tongue over my teeth to ensure my smile was not broken. Though not three seconds passed and I lost consciousness, immediately slipping into a deep coma.

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The Glasgow Coma Scale is used by health care providers to assess the depth and duration of impaired consciousness and coma (CDC “Glasgow Coma Scale”). The scale ranges from 3-15; the rating of an individual is determined by adding together the scores of three categories: motor response, verbal response, and eye opening. The final score of a patient on the Glasgow Coma Scale estimates the level of sustained injury.

After the paramedics had arrived at the scene of my car accident, I was evaluated at the lowest possible rating on the Glasgow Coma Scale. The collision with the tree had caused me to experience a very severe TBI. I was rushed to a local hospital, where it was determined that I was in desperate need of advanced medical care. I was then flown to Portland, Oregon where I was transferred to Doernbecher Children’s Hospital of Oregon Health & Science University (OHSU) and soon thereafter found myself under the care of an incredible staff and neurosurgical team.

I was fortunate enough that the people I avoided hitting by veering off the road had stopped and called 9-1-1 for me. They also took it upon themselves to drive to my home where
they notified my parents that their daughter has been in a terrible car accident. When I think about how they felt when a stranger knocked on the door and gave them that news, my mind grows numb and I become lost in thought about everything that happened. I cannot imagine the fear, anxiety, and distress that I caused my family and friends that day, and I will always be sorry for putting those I love the most through such turmoil.

I was 17 years old at the time, only a week away from starting my senior year of high school. Because my injury occurred at a young age and my brain was never deprived of oxygen, I suffered few physical consequences and was able to recover extraordinarily well. For many who sustain a brain injury, it is not the initial injury that causes damage; rather damage is caused by secondary injuries like lack of oxygen and cerebral edema (Ghajar 923). For the first eight or nine days of my hospitalization I was in a deep coma; my parents did not know if they would ever speak with their daughter again. The extent of my injuries remained unknown, and so my parents agonizingly thought through the possibilities. Is she paralyzed? Is she going to rise from the coma totally disabled? Is she ever going to rise from the coma?

This life-changing event happened on Labor Day, September the fifth. Ever since that fateful day in 2005, Labor Day has been a commemoration of another year alive for me, much more than any birthday has ever been. I would not be able to celebrate each Labor Day now if it weren’t for the strength and perseverance my parents and brother showed that day. If it weren’t for the help that our family and friends gave my family during that trying time, everything would have been impossibly difficult to handle alone. If it weren’t for the dedication to the art of healing that the medical professionals who cared for me have put forth in their lives, I would not have lived through such disastrous conditions. I am writing this research publication during my
final year of university study as a member of the University Honors College at Oregon State University. All of my personal, educational, and professional successes are a direct result of those who helped me along this path. I thank my family and friends for all that they have done, I thank all of my professors and advisers at Oregon State, and I thank the neurosurgery team at OHSU’s Doernbecher Children’s Hospital lead by Dr. Nathan Selden. If it weren’t for their expertise and receiving the best possible care at their hands I am sure that I would not have been able to achieve all that I have after the injuries I sustained.

To all of you who have touched my life, I thank you. I owe you everything.
TRAUMATIC BRAIN INJURY: ASSOCIATED PSYCHOLOGICAL CONSEQUENCES AND EFFECTIVENESS OF THERAPIES

TRAUMATIC BRAIN INJURY, A SILENT EPIDEMIC

Significance

According to the Centers for Disease Control and Prevention, approximately 1.7 million people sustain a traumatic brain injury (TBI) each year, of which 52,000 die, 275,000 are hospitalized, and 1.325 million are treated and released from an emergency department (“Statistics”). TBI accounts for one third of all injury related deaths and over 5.3 million people living with permanent disability as a result of the injury (Selassie, Zaloshnja, Langlois, Miller, Jones, and Steiner 123). According to the University of Pennsylvania’s Center for Brain Injury and Repair, there has been such an astounding increase of the incidence of TBI that the number of individuals suffering death and disability as a result of TBI now outnumbers that of breast cancer, AIDS, multiple sclerosis, and spinal cord injury combined (“TBI: A Silent Epidemic”).

Characteristics

TBI may affect the injured individual in a variety of ways, changing them physically and psychologically, either temporarily or permanently. The degree of change typically corresponds to the severity of injury; the most severely injured will be the most severely affected. Mild TBI does not have the drastic effects seen in more severe injuries,
though the outcome may still be debilitating as patients struggle with impaired problem solving skills, irritability, poor judgment, inability to relate to others, becoming easily distracted, and other related symptoms (Andrade et al.). Those affected by TBI can suffer from a wide range of debilitating consequences, some of which acute rehabilitation can lessen or alleviate, while some become permanent fixations in the injured person’s life. These consequences include, but are not limited to cognitive disorganization, disinhibition, decreased initiative, headaches, sleep disturbances, fatigability, amnesia, emotional withdrawal, social unawareness, agitation, inaccurate self-appraisal, anxiety, depression, expressive deficit or excess, hostility, suspiciousness, hallucinatory behavior, aphasia (impairment of expression and/or understanding of language), alternate and/or adverse personality, comprehension deficit, motor retardation, and/or partial or complete loss of any cognitive or motor skill. Physical complications may include any combination of physical deformations and/or circulatory, respiratory, musculoskeletal, sexual, or metabolic problems (Masel and DeWitt 1535). To compound matters further, the effects of TBI do not show a tendency to disappear over time and may even become more severe (Lippert-Grüner, Kuchta, Hellmich, and Klug 569).

Sustaining a TBI predisposes the injured individual to contracting various combinations and severities of neurological problems, including, but not limited to, neurological disorders including epilepsy and sleep disorders; neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease, dementia, chronic traumatic encephalopathy due to repeated brain injuries such as concussion (as happens in contact sports), and neuroendocrine disorders such as post-traumatic hypopituitarism (PTH), which leads to other neuroendocrine disorders such as gonadotropin and growth hormone
(GH) insufficiencies and hypothyroidism. Consistent with the indications of TBI, growth hormone deficiencies are connected to increased fatigue, lower tolerance for exercise, depression, osteoporosis, hypercholesterolemia, atherosclerosis, and a substantial rise in mortality due to vascular disease (Masel and DeWitt 1533).

Overall, TBI increases mortality and reduces life expectancy due to the psychological and physical changes that brain injury causes the affected individual’s body to experience (Masel and DeWitt 1529). Current estimates place the total cost of psychiatric illness at as much as one-third of the overall health care budget in the United States (Voshol, Glucksman, and van Oostrum 447). Since TBI is a leading cause of death and disability in this country (Thurman et al. 602), it is understandable that the overall cost of TBI (including direct and indirect costs) totals approximately $60 billion dollars annually (“Traumatic Brain Injury – Statistics”).

Above monetary losses, the ensuing physical and emotional cost of TBI for the injured and their loved ones is both indefinable and profound. Thus, it is in the best interest of those affected by brain injury and society at large to do everything possible to facilitate successful recovery from TBI. The recovery process begins with proper injury recognition and acute care, directly followed by administration of essential therapy for as long as necessary. In a study on cognitive decline in adults who have sustained a TBI, Till, Colella, Verwegen, and Green found that the best way to predict cognitive function success in the TBI patient was the amount of therapy received in the first five months post injury (S25), confirming earlier research that the first six months following brain injury is the most critical time for recovery (Ghajar 928; Burns 160). Sadly, many
patients do not receive sufficient therapy to help them recover from TBI, or they receive no therapy at all.

**Clinical Rehabilitation Data**

Current clinical practice regarding treatment and rehabilitation for TBI includes addressing acute needs using surgical intervention and/or placement of a cerebral drain to remove excess cerebrospinal fluid (Ghajar 926), or less invasive techniques such as placing the patient in a hypothermic environment to reduce the amount of cerebral swelling (Fox, Vu, Doyle-Waters, Brubacher, Abu-Laban, and Hu [Abstract]), introducing free-radical scavengers that remove injurious molecules whose release is triggered by injury (Hall, Kupina, and Althaus), or introducing pharmacological therapies with the goal of reducing cerebral swelling (Wakai, Roberts, and Schierhout 2) or manipulating the transmission of brain chemicals called neurotransmitters (Meythaler, Brunner, Johnson, and Novack 302). If rehabilitation therapy is administered, commonly any combination of speech-language pathology, psychological, occupational, behavioral, physical, and vision therapy is used. Even though most insurers will cover the acute care necessary to save the lives of brain-injured patients, many will not pay for the rehabilitation necessary for patients to fully recover from TBI, ultimately leading to a higher lifetime cost of care.

Aside from acute and subacute rehabilitative efforts, neuroprosthetics and assistive technology devices (ATDs) have proven to be an effective way to provide support and strengthen the deficits that the TBI patient is experiencing. Such devices
provide support for physical damage, such as cochlear implants for hearing deficits and neural implants that communicate wirelessly (Aravamudhan and Bellamkonda). A portable electronic device can provide support for cognitive damage by assisting, for example, with calendar and agenda planning.

In addition to traditional rehabilitation therapies and developing compensatory strategies to overcome the effects of TBI, long-term pharmaceutical therapies are often employed in an effort to balance altered neurochemistry. Prescription drugs are assigned to the affected individual based upon the symptoms they describe, which commonly include anxiety, depression, attention deficits, and mood disorders (Kile, et al.). Due to the difficult nature of obtaining prescription drugs and their cost, patients may resort to self-medicating with any combination of caffeine, supplements (such as energy drinks and/or enhancing agents), over the counter painkillers, and/or alcohol. Any combination of pharmaceutical agents or over the counter agents may be used by the brain injured patient in an attempt to regulate or escape the symptoms from which they suffer. Such disease management poses numerous threats to the health of the patient, subsequently incurring additional monetary and personal cost associated with the patient’s healthcare.

*Clinical Prognosis and Problem Statement*

The prognosis for the brain injured patient is often grim. There is a large discrepancy in the amount of people affected by brain injury and the amount of people admitted to therapeutic programs to heal their brain injuries (Sternberg). Most studies of the long-term effects of brain injury project a life riddled with persistent depression and
anxiety, inability to accomplish goals because of various psychological impairments, trying various combinations of pharmaceutical therapies, and in the end trapped in a never-ending struggle to regain some of the pre-injury life that is remembered as if it was a dream. Individuals who are unable to recover optimally from brain injury may be unable to adequately take care of themselves or dependents, resulting in an inability to live as independently and engage as productively in society as they did before they were injured. The persistent injured state of the TBI patient poses a problem for the patient, the patient’s family and friends, and society at large.

There is clearly a need for competent, comprehensive rehabilitative care for individuals who have experienced a TBI. Regrettably, many of the practices and approaches used for treating TBI in rehabilitative medicine today are ineffective, unsuccessful, and ultimately too brief. If their injury is properly recognized and diagnosed, TBI patients are habitually short-changed on the amount of therapy they receive.

Rather than a patient continuing therapy until the problems resulting from their brain injury are resolved as best as possible, many patients complete a treatment program up to a predetermined date or number of sessions and therapy does not continue beyond that point. Subsequently, many patients do not receive sufficient therapy to help them fully heal from their injury and are unable to reenter the workforce and/or social life, leaving them stranded financially, psychologically, and emotionally. Oftentimes the most severely disabled patients do not have outwardly visible impairments and are physically independent, but have such a high level of cognitive impairment they are unable to execute even rudimentary tasks without direction.
Currently, TBI is identified by health insurers and some healthcare providers as a single event, not an extenuating injury that requires continuous rehabilitation efforts (Masel, DeWitt). However, current research argues that brain trauma imparts upon an individual both a disease-causative and disease-accelerative condition (Masel, DeWitt 1529), even though it is considered to be a single event. Other conditions with such effects are considered ongoing events. Through first-hand experience and hearing the voices of other TBI patients who have also gone through various rehabilitation therapies, the author of this study aims to make the voices of TBI patients heard not through statistical representations or standardized test results, but simply by basing the main report on their personal accounts. This study aims to educate healthcare and research professionals about the patient’s perspective, reduce the feelings of isolation often felt among TBI patients by providing first person narratives from individuals who have also experienced TBI, and most of all positively impact rehabilitation practices for TBI with the ultimate goal of altering those practices for the better.
METHODS

This Study

This study researched the methods currently used to rehabilitate brain injured patients, the efficacy of those methods, how those practices affect the patient, and ultimately how those practices can change to provide a better experience for all individuals affected by brain injury. The primary research portion of this study was performed by collaboration between this author and neuroscientist Sarina Saturn, PhD. A comprehensive, anonymous online questionnaire asked brain injury patients about their injury specifics and used standardized quality of life and open response questions. Qualtrics online software was used (http://www.qualtrics.com/) to place this questionnaire into an anonymous online survey with multiple choice and/or free write response options in order to gather patients’ opinions on the rehabilitation they received and would like to see implemented. Participants were able to quit and resume the online survey as they pleased. No questions required a response to move to the next question; if a participant did not feel comfortable answering a question s/he could skip it and continue the survey. In this case, the response presented as blank in that participant’s result. Once responses were gathered, they were analyzed to detect commonly recurring themes. Participant responses were received from March to November 2011.
Research Participants

Survey participants (n=22, 18 women) were recruited for participation by presenting this study’s purpose and objectives to patient and practitioner attendees of the 9th annual Brain Injury Association of Oregon conference held in Portland, Oregon on March 4th and 5th, 2011. Institutional review board approval was obtained prior to presentation at this conference to ensure this study was in compliance with all related ethical standards. The stipulations for an individual to participate in this research survey were (1) the individual had to have experienced a brain injury at least once during their lifetime, and (2) the individual must have gone through some form of rehabilitation therapy as a result of that injury. Records of hospitalization or therapy administered were not sought to validate the research participant’s declarations of injury specifics, what therapy they received, or for how long they continued to receive therapy.

Among survey participants there was an even distribution of injury localization, time elapsed since injury, and age. Consistent with previous research on the causes of TBI, the majority of survey participants were injured in a motor vehicle crash (45.0%), followed by falls (14.0%), and violence (9.0%). Other causes of injury were motorcycle crashes (9.0%), bicycle accidents (5.0%), and external impact (5.0%). The cause of injury for several survey participants was not listed; these participants selected “other” in response and further explained their cause of injury. These causes were mistreated ear infection that resulted in Lemierre’s syndrome and Cerebral Venous Sinus Thrombosis; brain tumor operation; medical neglect resulting in cerebral edema lasting 10 days and the patient suffering at least one stroke; and physical assault at the patient’s workplace.
Research Questions

Initial survey questions requested information on individual and injury specifics such as: gender and age, how long ago the injury occurred, injury localization, how the respondent was injured, if the respondent received inpatient or outpatient therapy, and what therapies were received. For each multiple-answer question, checkboxes were provided to allow more than one response to the same question. For example, a respondent could check physical and speech if both were received or if their extended answer pertained to both therapies. The respondent then answered qualitative questions concerning their experience in rehabilitation and the ways that rehabilitation affected them.

All questions pertaining to injury specifics and therapy were originally formulated by this author and advisor. Subsequent questions pertaining to current quality of life, perceived stress, and coping capabilities were derived from established psychological scales such as Ryff Scales of Psychological well-being (1989), Perceived Stress by Cohen et al. (1983), and Implicit Theories of Stress Coping for Self developed by Dr. Saturn and colleagues at the University of California, Berkeley (2009).
RESULTS

Survey Responses

Our results from qualitative multivariate analysis of survey responses reveal that the current prescribed duration of rehabilitation therapy for TBI is too short, more time in rehabilitation must be spent working towards specific goals, and in agreement with Braverman et al. (406), a multidisciplinary, multidirectional approach is vital to the successful recovery of the brain injured patient. The overall patient sentiment concerning rehabilitation therapy articulates that therapy overall was inadequately designed, too short in duration, and/or the patient did not receive sufficient therapy to address the effects of their brain injury. Patient participants also felt that brain injury is largely misunderstood by the rehabilitation professionals they sought help from and that more education in the healthcare field is required for healthcare professionals to be able to offer competent care for brain injured individuals. Most of this study’s participants felt as though practitioners did not know how to treat brain injury specifically or even understood brain injury.

Following the quantitative injury and therapy questions, qualitative questions regarding therapy received and quality of life post-injury were asked.

Most Beneficial Therapy

When asked what therapy they believed they received the most benefit from (Appendix A), patients’ responses were cognitive (n=8), physical (n=5), psychological (n=5), speech-language (n=3), occupational (n=1), or other (n=4) therapy. Patients were offered
a text box to specify the “other” therapy they believed they received the most benefit from. Entered responses to this category were vision, balance, craniosacral, acupuncture, cranial, and massage therapy. Patient participants believed that therapies were most beneficial when multiple therapeutic approaches were used, they worked in unison, and were individually tailored to their own specific needs. This is communicated in one survey participant’s response when describing why the therapies she received were beneficial:

“… [Because therapies] complement each other, and techniques learned in each overlap and apply to the other areas … my cognitive rehab therapist, vision therapist, and counselor … respond to my changing needs quickly, treat me compassionately and respectfully, respond to my concerns and requests about them or the therapy activities, and tailor treatment to me as an individual … especially beings most people simply don't understand what it means to have a brain injury.”

Another conveyed these same thoughts in saying, “Every brain injury is different therefore when therapy for brain injury is individualized it is the most beneficial.”

Also asked was which therapy the participant liked the most and why (Appendix B), and which therapy the participant disliked and why (Appendix C). Responses to these questions depended largely on which therapy the patient could notice the most benefit from. If a patient could not perceive any benefit or could not understand how the therapy applied to their needs, they did not enjoy whatever therapy they received.

Current Quality of Life

Agreement to statements concerning quality of life were recorded based on a five-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly
disagree). Based upon responses to these questions it was determined that the majority of post-TBI patients feel unable to keep up with the responsibilities of their daily life, are not able to organize their responsibilities or time in a way that allows them to accomplish what they need to do, and ultimately feel defeated by the demands of everyday life. For example, agreement to the statement “I find it stressful that I can't keep up with all of the things I have to do each day” yielded 50% of respondents strongly agreeing, 13% agreeing, 13% neither agreeing or disagreeing, 13% disagreeing, and 13% strongly disagreeing. When asked to rate agreement with the statement “I often feel overwhelmed by my responsibilities,” 38% of respondents strongly agreed, 25% agreed, 13% neither agreed nor disagreed, 13% disagreed, and 13% strongly disagreed. Appendix D displays specific responses to statements relating to current quality of life.

Respect in Therapy

In addition to therapy-specific questions, therapist-specific questions were asked concerning the relationship patients had with their therapists. The majority of patients had a good relationship with their therapists, yet some did not because of personality conflicts and issues of disrespect. In general, patients felt respected by their therapists, yet of eight respondents there were three significant cases in which the participant reported feeling disrespected by their therapist(s). One participant’s response shows well the issues that arise concerning lack of respect from practitioners:

“I felt ‘talked down to’ by some therapists … I feel the OTs treated me with more respect than others. Some speech therapists were arrogant (as if they ‘knew best’). Neuropsychologists and neurologists were the most disrespectful. My biggest complaint is with speech therapists who gave me
‘strategies’ but seemed to blame me when they didn't work. … I now know that this happened because they only understood basic principles, but not how to implement their suggestions at the tactical level, based upon what works in a real-world setting.”

In similar cases, the disrespectful therapist may have spent appointment time doing unrelated tasks, were not respectful of the patient’s brain injury-specific needs, and/or did not acknowledge the patient’s brain-injured condition as a reality. Appendix E displays complete survey responses to questions regarding respect.

**Suggested Changes to Therapy**

After patient opinions were gathered on the therapy they received, survey participants were asked if they believed they would have healed more successfully if the therapy they received had been different. Of eight responses, three thought “Definitely” they would have healed more successfully, one thought “Probably,” one “Probably not,” and three replied “No, the therapy used worked well for me.” The question was posed to survey participants if they have any ideas to incorporate into existing therapeutic programs or for new therapeutic methods (Appendix F). Patients believe there should be more cooperation between the therapeutic realms by increasing the amount of referrals and implementation of whatever therapy has the possibility of helping the patient, there must be a better understanding of brain injury by treatment specialists, and ultimately therapists need to listen to the individual patient in order to know how to best help their healing efforts. After going through extensive therapy, this survey participant has many ideas for ways to help the brain-injured patient resume pre-injury status:
“Being given specific TACTICS to compensate that are known to work over time. Not general principles like, 'get organized,' ‘write stuff down,’ ‘use visual cues,’ etc. Because cognitive therapy at the tactical level works and instruction in general principles less so. I received 6+ hours per day of therapy (all forms), 6 days per week for 5 months, then approximately 10 hours per week of outpatient therapy for 9 more months. That totals 775 hours in residence and 400 hours as an outpatient. That adds up to almost 1,200 hours of therapy. I had support to practice compensatory skills that I estimate to be another 1,200 hours. That's close to 2,500 hours of therapeutic services. I returned to entry-level work after two years, and achieved my former functional level (WITH strategies) after about 7 years. With tactical-level support, I estimate this could have been cut to 500 hours total overall.”

As evidenced by this study’s survey responses and established clinical research data, it is evident that all-encompassing, long-term therapy is what helped this brain-injured patient return to their pre-injury lifestyle and what will help other brain injured patients also heal successfully. The necessity for the therapist to listen to the individual patient has been stated countless times in this study’s results as well as in already established research data and cannot be ignored.
DISCUSSION

*Every TBI is unique*

As an individual who has experienced all aspects of brain injury from the initial stages of injury and inpatient and outpatient therapy to brain injury researcher, I understand firsthand that the mechanisms of TBI are not fully understood, the impact of TBI utterly unpredictable, and the outcome of each case of TBI is as unique as the individual who sustains the injury. It is because of this uniqueness that those who have experienced TBI are also not fully understood. The physical mechanisms of brain injury on a cellular level are known and the psychological sequelae notorious; however brain injury remains intangible even to those closest to it. Individuals who have experienced a TBI feel misunderstood by friends, family, and the medical professionals that try to help them. This misunderstanding leads to the individual being underserved by the medical community and incapacitated by the aftermath of their injury.

*Treat an individual, not an average*

If brain injury is properly diagnosed and the necessary rehabilitation therapy is assigned, too often little to nothing is done beyond the acute and subacute stages of injury to help TBI patients recover. This leaves many patients to fall between the cracks after insurance coverage is exhausted or they reach a pre-determined benchmark based not on their individual case but rather on rehabilitation statistics. Statistics embody averages, not individuals, and rehabilitation therapy does not serve an average, it serves an individual.
Therefore, each rehabilitation regimen must be individually tailored to the patient’s specific needs. This study found that unless the patient is enrolled in a TBI-specific rehabilitation program, which is expensive and not often covered by health insurance companies, the therapies administered tend to be too general and do not adequately target specific medical, cognitive, psychosocial, and behavioral issues that arise. Generally, the main symptom of TBI is loss of cognitive function, be it conscious or subconscious; however therapeutic goals rarely include cognitive recovery (Burns 160). Tailoring therapeutic regimens to fit the individual’s specific needs should be a somewhat easy task. However, there are so many institutional limitations on the formulation of a therapeutic regimen; individuals are often restricted to receiving only certain types of therapy, while others that could benefit them greatly are excluded.

Non-traditional therapies

Not all therapies for TBI fall under the category of typical Western medicine; naturopathic provider Andy Swanson of Portland, Oregon has seen great success in improving the brain injured patient’s life by controlling dietary intake and using Eastern techniques such as acupuncture to reduce the frequency and severity of symptoms (Swanson). Another example of a nontraditional therapy that has proven effective in the treatment of TBI is hyperbaric oxygen chamber sessions. Sessions in a hyperbaric chamber increase the oxygen saturation of tissues by enclosing the patient in a pressurized 100% oxygen environment (Huang & Obenaus). An additional complementary therapy is engaging the patient in neurofeedback sessions where readings
of brain activity are displayed to the patient on a computer screen (Congedo, Lubar, and Joffe).

A biological alternative therapy that has proven effective in the treatment of many conditions but has not yet come to fruition in the United States for human medicine is stem cell therapy. Animal and human studies have shown that the introduction of stem cells to the injured subject’s body helps damaged tissues recover after TBI (Cox et al.) and recovery of central nervous system tissue damage in general (Selden). The stem cells used in such studies were sourced from different origins, including adipose tissue (“Adipose-derived Stem Cells”), bone marrow (Cox et al.), and human umbilical cord stem cells derived from the umbilical vein postpartum (Eve, Sanberg, and Willing). Though however effective preliminary studies have shown them to be, such treatments are not recognized by health insurance as viable therapies for recovery from TBI and are therefore not covered. Patients pursuing any healing modality that insurance does not acknowledge must pay for those therapies out of pocket, leaving many patients unable to afford therapeutic treatments beyond the prescribed regimen.

Comprehensive empowerment

Continuing therapy far beyond the acute stages of injury and healing are needed to best recover from TBI. Incorporating all therapies that appropriately challenge the healing brain in as many ways possible is a necessity. Extended periods of rehabilitation that utilize all therapies included in the patient’s recovery in cohesion as well as addresses specific deficits shows the most promise for optimum recovery from TBI.
Recognition and incorporation of nontraditional therapies like nutritional control, hyperbaric oxygen therapy, neurofeedback, and stem cell therapies to complement traditional therapies will be vital to the complete recovery of the TBI patient. Such methods will empower patients to resume their pre-injury lifestyle by invigorating the patient psychologically and physiologically.

Assumptions and Limitations

This study did not adhere to a stringent qualification process in choosing research participants. All participants volunteered to participate in the research survey, and information concerning how to proceed was given to those volunteers. This survey was not taken in a controlled environment, therefore it was not validated that all individuals who completed the survey had indeed experienced a brain injury and gone through therapy as a result of that injury; it was assumed that only such individuals elected to participate.

Limitations that hindered this study include constraints on how extensive the survey was able to be, thus limiting the amount of detailed questions asked of the survey participants. There were also geographic constraints as survey respondents were only recruited in the Portland, Oregon area. While some respondents offered very thorough responses, some very succinctly answered the question posed and did not offer much more detailed information. Knowing that there are many different aspects to each case of a traumatic event, the limited responses lent only a small amount of insight to a much larger unseen circumstance.
RECOMMENDATIONS

This author recommends population-based studies be conducted to further confirm the efficacy of non-traditional therapies in order to endorse their incorporation into mainstream rehabilitative practices. Additionally, further studies like this one on the patient’s perspective of rehabilitation practices should be conducted to affirm and add to this study’s findings. Furthermore, a TBI training requirement is recommended to be added to continuing education courses for all healthcare professionals who may work with TBI patients. If providers understand the depth and extent even a seemingly minor brain injury can have on the affected individual’s life, more precise diagnosis and subsequently more effective rehabilitation efforts can be made for these individuals. The need to appropriately identify and assess brain injury during the acute stages has been identified by many, yet there remains a great divide in the recognition of brain injury initially, the persistence of brain injury, and thus the appreciation of the amount of therapy needed to recovery. While one may survive the initial injury, one does not survive the aftereffects of TBI alone. This study aims to improve rehabilitative therapies used for TBI by making the smallest voice heard, that of the patient.
REFERENCES


Cox, Charles S., James E. Baumgartner, Mattew T. Harting, MD, PhD, Laura L. Worth, MD, Peter A. Walker, Shinil K. Shaw, DO, Linda Ewing-Cobbs, PhD, Khader M. Hasan, PhD, Mary-Clare Day, RN, BSN, Dean Lee, MD, PhD, Fernando Jimenez, MS, and Adrian Gee, PhD. “Autologous Bone Marrow Mononuclear Cell Therapy for Severe Traumatic Brain Injury in Children.” Neurosurgery 68 (2011): 588-600. Print.


Appendix A: Most Beneficial Therapy

<table>
<thead>
<tr>
<th>Therapy believed to be most beneficial</th>
<th>Patient Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical, Speech-language, Psychological</td>
<td>“I wanted to be able to return to work so was more driven to regain my physical ability and memory.”</td>
</tr>
<tr>
<td>Physical, Speech-language, Vision</td>
<td><em>Mother completing survey for her brain injured daughter:</em> “All three therapies were vital to my daughter’s recovery. Her processing time was so slow, she needed therapy 3-5 times per week, and it did pay off eventually. The vision therapy was vital, one of her eyes was not tracking as it should … the physical therapy was needed, balance was so far off, and she had very little stamina. All three therapies worked together to put her back into a whole functioning person.”</td>
</tr>
<tr>
<td>Speech-language</td>
<td>“Speech was used as cognitive rehab substitute [sic]. I had a skilled speech therapist who was a good advocate.”</td>
</tr>
<tr>
<td>Psychological, Cognitive, Vision</td>
<td>“These three … complement each other, and techniques learned in each overlap and apply to the other areas … my cognitive rehab therapist, vision therapist, and counselor … respond to my changing needs quickly, treat me compassionately and respectfully, respond to my concerns and requests about them or the therapy activities, and tailor treatment to me as an individual … especially beings most people simply don’t understand what it means to have a brain injury.”</td>
</tr>
<tr>
<td>Physical, Psychological, Speech, Vision, Cognitive</td>
<td>“All therapies were helpful. I had multiple injuries so all treatments were both necessary and beneficial.”</td>
</tr>
<tr>
<td>Physical, Cognitive</td>
<td>“Due to the specific therapists and if they actually listened to the individual or if they just went off a specific to do list [determined therapy helpfulness] … My brain froze with written math so I brought flashcards and asked if they could help me in this area. I was told no. Every brain injury is different therefore when therapy for brain injury is individualised [sic] it is the most beneficial [sic].”</td>
</tr>
<tr>
<td>Physical, Occupational, Speech, Psychological, Cognitive</td>
<td>“They were all encompassing as well as I was advancing in recovery at very fast pace more so than what the specialist knew what to do.”</td>
</tr>
<tr>
<td>Speech-language</td>
<td>”Speech was used as cognitive rehab substitute. I had a skilled speech therapist who was a good advocate.”</td>
</tr>
<tr>
<td>Procedure</td>
<td>Testimonial</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Speech-language</td>
<td>“Because it [speech-language therapy] challenged me mentally, I developed more critical thinking skills because of those challenges.”</td>
</tr>
<tr>
<td>Physical, Occupational, Psychological, Cognitive, Speech-language</td>
<td>“Learning compensatory strategies for memory and executive function challenges has had the most benefits with respect to regaining autonomy and eventually returning to work at my previous level.”</td>
</tr>
</tbody>
</table>
## Appendix B: Therapy most enjoyed and reason for enjoyment

<table>
<thead>
<tr>
<th>Therapy most enjoyed</th>
<th>Patient Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological, Cognitive</td>
<td>“I could see improvement in both areas easier than I could with the physical therapy.”</td>
</tr>
<tr>
<td>Psychological</td>
<td>“Taught me how to deal with the changes in my life.”</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td><em>Mother completing survey for her brain injured daughter:</em> “My guess is that PT … was her favorite, because … [the therapist] was always so positive, and worked with [her] carefully on her good days and bad days.”</td>
</tr>
<tr>
<td>Neurofeedback</td>
<td>“I experienced immediate results after each visit. It was nice to know that I was doing something that was working.”</td>
</tr>
<tr>
<td>Occupational</td>
<td>“I liked the practicality of Occupational Therapy … it allowed me to practice the cognitive skills I learned from my speech therapists.”</td>
</tr>
<tr>
<td>Vision</td>
<td>“I perceive progress and improvement in this area the quickest. The clinician gives a lot of positive feedback about my improvements, but it's never platitudes and random &quot;good job&quot; or &quot;wow, you're doing better&quot; like some of my other clinicians give me. That feedback just beats me down and does not inspire me when I make a mistake and get told &quot;good job&quot;. The vision therapist gives not too much, not too little for positive reinforcement and allows me to make my own discoveries and form my own opinions about myself.”</td>
</tr>
<tr>
<td>Vision, Vestibular</td>
<td>“All were helpful, but the most helpful were the vision therapies and the vestibular therapy.”</td>
</tr>
<tr>
<td>Physical, Psychological, Speech, Vision, Cognitive</td>
<td>“All therapies were helpful. I had multiple injuries so all treatments were both necessary and beneficial.”</td>
</tr>
<tr>
<td>Physical, Occupational, Speech, Psychological, Cognitive</td>
<td>“They were all encompassing as well as I was advancing in recovery at very fast pace more so than what the specialist knew what to do.”</td>
</tr>
<tr>
<td>Physical, Cognitive</td>
<td>“Due to the specific therapists and if they actually listened to the individual or if they just went off a specific to do list. For example the occupational therapist had me make copies 30 each of about 10 different ones. I could make copies fine so it was a waste of time. My brain froze with written math so I brought flashcards and asked if they could help me in this area. I was told no. I was told to bring my makeup and curling iron though. I was taking showers, washing hair, shaving, brushing teeth. I was not putting on makeup or curling hair due to the amount of energy it took which I would rather put to regaining things I lost. Every brain injury is different therefore when therapy for brain injury is individualized it is the most beneficial.”</td>
</tr>
</tbody>
</table>
Appendix C: Disliked therapy and reason for dislike.

<table>
<thead>
<tr>
<th>Therapy most disliked</th>
<th>Patient Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not specified</td>
<td>“[I disliked it] when I was asked to do ‘brain train’ types of exercises to ‘strengthen’ organic brain function. They made me feel suicidal because instead of compensating and empowering me, they pointed out my deficits and didn't strengthen anything cognitively … In hindsight, it seems akin to exercising a sprained ankle.”</td>
</tr>
<tr>
<td>Occupational</td>
<td>“Because they were trying to push me into a work environment which I did not like and I still had more healing to do.”</td>
</tr>
<tr>
<td>Speech</td>
<td>“Because the therapist had me do things which I had no problem with or were not concerns as I had so many other concerns.”</td>
</tr>
<tr>
<td>Speech</td>
<td>“I had a really ha[r]d time with occupational therapy, I found the exercises didn't really work for me. I had really high expectations of my care and felt that the tasks they were having me do really weren't helping me to get back to where I wanted to be. I was so unbelievably frustrated with this part of my therapy. I had an incredibly had time with my short term memory and had gone back to school and simply felt that my needs weren't being met.”</td>
</tr>
<tr>
<td>Physical, Psychological, Cognitive</td>
<td>“… all were generalists, did not address my specific needs, seemed to have little if any information regarding mile head trauma or arthritis”</td>
</tr>
<tr>
<td>Physical, Occupational</td>
<td>“One [therapist] was incapable of communicating clearly with someone with acute brain injury … Most importantly, although all of them noted my severe anxiety and agitation, only one recommended psych services … The occupational therapist … never remembered week to week whether I’d last seen her, did the same therapy activities over and over, kept her office excessively cluttered (hard to do vision exercises with clutter) … did not return calls, read other people's emails during my office visit, and spent significant time asking me to breathe deeply, relax, and say positive affirmations but NEVER suggested psych services.”</td>
</tr>
<tr>
<td>Speech, Medication</td>
<td>“I don't like taking the medication because of the side effects, however without it I wouldn't be functioning at the level that I am now. I now remember my son and husband. I also completed a master’s degree and have been working for about 3 years now. I didn't like the speech because I didn't get anything out of it that I didn't already know.”</td>
</tr>
</tbody>
</table>
Appendix D: Current Quality of Life.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am quite good at managing the responsibilities of my daily life</td>
<td>17%</td>
<td>44%</td>
<td>0%</td>
<td>28%</td>
<td>11%</td>
</tr>
<tr>
<td>I find it stressful that I can’t keep up with all the things I have to do each day</td>
<td>6%</td>
<td>11%</td>
<td>0%</td>
<td>17%</td>
<td>39%</td>
</tr>
<tr>
<td>I often feel overwhelmed by my responsibilities</td>
<td>6%</td>
<td>22%</td>
<td>11%</td>
<td>28%</td>
<td>33%</td>
</tr>
<tr>
<td>I am good at juggling my time so I can fit in everything that needs to get done</td>
<td>28%</td>
<td>22%</td>
<td>11%</td>
<td>33%</td>
<td>6%</td>
</tr>
<tr>
<td>I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do</td>
<td>13%</td>
<td>13%</td>
<td>13%</td>
<td>50%</td>
<td>13%</td>
</tr>
</tbody>
</table>
### Appendix E: Respect in Therapy

<table>
<thead>
<tr>
<th>Patient response</th>
<th>Patient explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Sometimes I felt I was treated with disrespect”</td>
<td>“One PT and the OT were most disrespectful. But still, when I started telling my physician (who did a fellowship in concussion management) and my PT that I felt like perhaps a few of my impairments were psychogenic, they both ignored me, the PT calling me a &quot;control freak.&quot; I did my own research into many of my symptoms in the peer reviewed medical journals and visited a neurologist who confirmed my assumption. … If I didn't have the background medical knowledge or access to these journals, I would be stuck here with almost no information about my own condition. A respectful clinician should explain your condition to you and help you contextualize it.”</td>
</tr>
<tr>
<td>“Most of the time I felt treated with respect”</td>
<td>“I felt she [vestibular therapist] was the most aware of what I needed and how it affected me. One physical therapist whispered in my ear which was very upsetting to me..... I got the impression she thought she was getting ‘to my brain better’ or something....but I didn't like it at all. Also the first neuropsych I had was the best … always treated me like I was a human being and like he believed me, etc.”</td>
</tr>
<tr>
<td>“Most of the time I felt treated with respect”</td>
<td>“I felt ‘talked down to’ by some therapists … I feel the OTs treated me with more respect than others. Some speech therapists were arrogant (as if they &quot;knew best&quot;). Neuropsychologists and neurologists were the most disrespectful. My biggest complaint is with speech therapists who gave me ‘strategies’ but seemed to blame me when they didn't work … I now know that this happened because they only understood basic principles, but not how to implement their suggestions at the tactical level, based upon what works in a real-world setting”</td>
</tr>
<tr>
<td>“Most of the time I felt disrespected”</td>
<td>“Espeicially [sic] the psychologist and neuropsychologists who told me all of the problems were anxiety based or psychological… [There was a] lack of willingness to know me as an individual, [I was] tested according to norms for my age not according to my own norm, [I was] never asked about prior level of function or my goals.”</td>
</tr>
<tr>
<td>“I always felt treated with respect”</td>
<td>“In the beginning [sic] I felt as if I wasn't being heard, I kept being told that I was fine and would be back to normal in three months, then six, then nine to twelve and so on. It was so incredibly frustrating because I knew that I wasn't right and I wasn't being heard, I think this was valuable time that was wasted when I could have been making a lot more progress instead of simply wasting away. Once I finally got the attention of my doctors and convinced them that something was indeed wrong with me and I was able to get in with good medical professionals I was always treated with respect.”</td>
</tr>
</tbody>
</table>
### Appendix F: Suggested Changes to Therapy

<table>
<thead>
<tr>
<th>Therapy patient participant would change</th>
<th>Why patient believes said therapy should be changed and proposed changes to that therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical, Occupational</td>
<td>“From the PTs and OT, referral to psych services from the very beginning OR sending a note to my physician to screen me for psychological dysfunction (whether organic to the injury or as a result of the injury) absolutely immediately instead of the out of scope of practice behavior they exhibited of commanding me to breathe deeper, breathe slower, put my hand on my heart, and repeat positive statements. Also, they should have referred me to the SLP for cognitive rehab months earlier as they noticed I was disorganized and confused. Or they should have at least told her I was so confused. The OT should absolutely NOT been attempting vision therapy with me, as she was unsupervised and hardly trained in any of the techniques. I should not be billing insurance to be someone's clinical experiment without signing a consent form. No clinician should EVER be allowed to make suggestions or give instructions regarding benefits, leave, disability, or anything else without consulting Human Resources first. I do not care how much training they have in ADA or anything regarding that particular workplace. It is unacceptable to answer questions and dispense advice and call it therapy when they have not consulted with the experts. I should have been given instructions to ask HR myself.”</td>
</tr>
<tr>
<td>Psychological</td>
<td>“The only improvement I can say is needed is that the Dr who treated my psychological problems was very, very good. HOWEVER, I sometimes felt that he didn't seem to believe or understand that I had a TBI. I did discuss it with him at the end. I don't feel it interfered with my treatment, but I do feel he was wrong and didn't understand my TBI.”</td>
</tr>
<tr>
<td>Psychological</td>
<td>“Individuals providing psychological therapy to patients with brain injury should educate themselves on what brain injury is, and what techniques/perspectives are helpful in working with these patients. They should also take care to treat patients with respect.”</td>
</tr>
<tr>
<td>Speech, Occupational</td>
<td>“I believe it comes down to listening to the individual as each brain injury is individual and working with them to regain what is lost. They and their loved ones know what they were like prior and what has changed or is now lost. For example I had a 138 IQ prior. Afterwards 107 which is 31 down. Also my past strengths are now my weaknesses. So instead of saying 107 is normal look at what is lost and work to regain. Because it is not normal for me. LOOK AT AND LISTEN TO THE INDIVIDUAL! Because brain injuries are different in everyone.”</td>
</tr>
<tr>
<td><strong>Physical, Occupational, Psychological</strong></td>
<td>“Cognitive help with dealing with some things in life, physically there was not much done and now that I'm getting older it's hard to do things. Also living alone is tough. For better mental health &amp; physical health I'm responsible for my own health care if I don't ask for help I will never get it until I'm in deep trouble the insurance companies know this they just let people flounder with life and if you have no family you need help to keep an eye on you, not a baby sitter, but proper care.”</td>
</tr>
<tr>
<td><strong>Vision Cognitive</strong></td>
<td>“More cognitive and vision therapies, these are areas I still struggle with.”</td>
</tr>
<tr>
<td><strong>Cognitive</strong></td>
<td>“Being given specific TACTICS to compensate that are known to work over time. Not general principles like, ‘get organized,’ ‘write stuff down,’ ‘use visual cues,’ etc. Because cognitive therapy at the tactical level works and instruction in general principles less so. I received 6+ hours per day of therapy (all forms), 6 days per week for 5 months, then approximately 10 hours per week of outpatient therapy for 9 more months. That totals 775 hours in residence and 400 hours as an outpatient. That adds up to almost 1,200 hours of therapy. I had support to practice compensatory skills that I estimate to be another 1,200 hours. That's close to 2,500 hours of therapeutic services. I returned to entry-level work after two years, and achieved my former functional level (WITH strategies) after about 7 years. With tactical-level support, I estimate this could have been cut to 500 hours total overall. My rehab cost my insurance company over $500,000. My injury was on the low end of &quot;Moderate&quot; using the Glasgow Scale.”</td>
</tr>
<tr>
<td><strong>Cognitive</strong></td>
<td>“I had more expectations from cognitive therapy, I guess that I was expecting to learn how to learn, strategies to work with my lack of short term memory, how to deal with all of the deficits that I had (all of which I could tell the therapists and were backed by my testing). I don't really feel that I got this type of therapy out of cognitive therapy; the therapists didn't push past what didn't work for me. I think that changes need to be made because not everyone benefits from the same type of therapy. If one strategy doesn't work then therapists should try another one they shouldn't simply give up or ignore the problem.”</td>
</tr>
<tr>
<td><strong>Therapy Not Specified</strong></td>
<td>“All therapies were helpful to some degree. Some of the therapists seemed to have their own problems. The therapists outside the hospital were much better than the ones in....but that seemed to be because they only were required to get me to a certain point to get me out of the hospital.... not to make my life bearable. The system is getting worse and collapsing. Especially the psychologists...... training maybe, DSM crap maybe..... not weeding out those who are going for degrees that have too many problems of their own.....”</td>
</tr>
</tbody>
</table>
| Therapy Not Specified | “The one area that seems to ring back to the forefront constantly is trying to understand what being labeled a T.B.I. means in getting back to normal society living. Education of the general populace. It does not bother me to be a T.B.I. or being labeled as a T.B.I. What is incredible is the lack of understanding from the general populace of being a T.B.I. People are so conditioned that to be a disabled person with whatever type of impairment you must have a bandage a wound or some type assisting device to be disabled. When it is your brain with no visible affects than there should be nothing wrong with that person.”

Mother completing survey for brain injured daughter: “Originally we had a different insurance plan, and got very little help for my daughter for an entire year. We were finally able to get 6 weeks of sparse therapy, with therapists who, although nice, didn't seem to think she would get better, but wanted to help her to learn to deal with her issues. I don't feel this group of therapists were trained to deal with TBI's, and recovery. It was a complete waste of our time and money. After we switched out insurance plan, we got the kind of help that she needed.”

“Some health facilities are not up to date on the benefits of therapy to aid in recovery. Our old plan had the notion that it will just take time. We wasted a year of her life waiting for time to pass for her to get better, and there ended up being NO PROGRESS at all.”

“Transferrable generalizable compensatory skills training and as early as possible. I wouldn't have failed so many times before had I known what I know now”

“Early intervention and specific strategies and tactics that can be generalized. More use of assistive technology. These are the things that I have found on my own and that have worked for me.”

“True cognitive rehabilitation should be a right for all individuals with brain injury. While many therapies do pieces of cognitive rehab, few tie the importance of improving your cognitive skills to how successful all other outcome measures.”

“That everyone who hits their head and exhibits brain injury symptoms is properly diagnosed and referred to all applicable therapies. Because I had two brain bleeds, a subdural hematoma and subarachnoid hemorrhage, and I was diagnosed with "MAJOR DEPRESSION." I was failed by the medical community.”

| Would change all therapies | Again access prior level of function, routines, goals, especially evaluate in normal situations, multitasking, when fatigued. If I was not an OT and had OT friends and paid privately to go to USC, the Legacy therapists and progressive rehab never tested function in normal situations |
Dear Research Contributor,

I personally thank you for participating in this research study by someone who has suffered from brain injury and is working to help those who have also experienced brain injury. The informed consent form below details survey protocol, following it is the survey gathering your opinion of your therapists and the rehabilitation you received.

I truly appreciate the time and effort you put into completing this survey. Your responses are the main component of this research and will largely shape an evaluation of current therapeutic techniques, as well as help form propositions for brand new therapies.

Thank you very much for your time and effort to contribute.

Together, we can make a difference!

Jessica Hansen
severe traumatic brain injury survivor.
September 2005

INFORMED CONSENT FORM

Project Title: Traumatic Brain Injury: Associated Psychological Consequences and Effectiveness of Therapies.

Principal Investigator: Sarina Rodrigues, PhD
Student Researcher: Jessica Hansen

Version Date: 2/28/2011

1. WHAT IS THE PURPOSE OF THIS FORM?

This form contains information you will need to help you decide whether to be in this study or not. Please read the form carefully and ask the study team member(s) questions about anything that is not clear.

PARTICIPANTS MUST BE 18 YEARS OF AGE OR OLDER IN ORDER TO PARTICIPATE IN THIS STUDY.

2. WHY IS THIS STUDY BEING DONE?

The purpose of this study is to examine current therapies used for patients who have suffered from a brain injury. Injury location as it relates to experienced psychological side effects and the therapies currently used to help patients who have suffered from brain injury will be analyzed, as well as suggesting changes...
to these therapies or addition of new therapies. A holistic approach to understanding the patient experience of their injury will be taken, and emphasis will be placed on patient accounts of the injury experience. The student researcher conducting this study experienced a severe traumatic brain injury five years ago and is assessing the therapeutic techniques currently in place based upon the patient’s accounts of the injury experience. The knowledge collected from patients who have suffered traumatic brain injury, as well as the personal experience of the student researcher, will be used to make suggestions for changes to current techniques and encourage new therapies to help victims of traumatic brain injury.

The study is being conducted by an Oregon State University Honors College student to fulfill the requirement of a thesis.

3. WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY?

You are being invited to take part in this study because of your personal encounter with brain injury. You can contribute greatly to this study by sharing your opinions of the experience you had both in the hospital and at home during recovery. Your opinions and responses to these research questions will be used to analyze current methods used by health care professionals to help those who have had a traumatic brain injury, as well as to make suggestions for changes to those methods or suggest new methods.

4. WHAT WILL HAPPEN IF I TAKE PART IN THIS RESEARCH STUDY?

If you choose to participate in this study, you will complete an anonymous questionnaire about your injury, therapies you received in the hospital and continuing therapy outside of hospitalization, and your opinions on those therapeutic methods.

The total time needed to complete the survey from start to finish will be a minimum of 10-15 minutes. The amount of time you will need to complete the survey is dependent on the depth of response you provide to each question.

5. WHAT ARE THE RISKS AND POSSIBLE DISCOMFORTS OF THIS STUDY?

The possible risks and/or discomforts associated with the being in the study include distress or discomfort when recalling items of a personal nature, and the inconvenience associated with finding time and space to comfortably respond to the survey questions.

6. WHAT ARE THE BENEFITS OF THIS STUDY?

We do not know if you will benefit from being in this study. However, you may receive indirect benefit from contributing to the understanding of the patient experience of traumatic brain injury and the therapies used to help those who have suffered from it, as well as contributing to the development of potential new therapies.
7. WILL I BE PAID FOR BEING IN THIS STUDY?

You will not be paid for being in this research study.

8. WHO WILL SEE THE INFORMATION I GIVE?

Although some questions may involve sensitive information about your hardships, please be assured that we are NOT asking for any identifying information that could link you in any way to the data you provide. The survey you will complete is entirely anonymous; it will only ask you questions pertaining to the research topic, no identifying information will be recorded.

Your responses to the questions will be identified by a number. Responses will be stored securely and only researchers will have access to the records. Federal regulatory agencies and the Oregon State University Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. None of these records will contain information that personally identifies you.

If the results of this project are published, your anonymous individual responses may be published to serve as examples of the opinions of individuals who have suffered from traumatic brain injury.

9. WHAT OTHER CHOICES DO I HAVE IF I DO NOT TAKE PART IN THIS STUDY?

Participation in this study is voluntary. If you decide to participate, you are free to skip any questions you would prefer not to answer. In addition, you are free to withdraw at any time you wish without penalty.

10. WHO DO I CONTACT IF I HAVE QUESTIONS?

If you have any questions about this research project, please contact:
Jessica Hansen (student researcher) email: jch0326@gmail.com; phone: (503)-529-1118
Dr. Sarina Rodrigues, email: sarina.rodrigues@oregonstate.edu; phone: (541)-737-1366.

If you have questions about your rights or welfare as a participant, please contact the Oregon State University Institutional Review Board (IRB) Office, at (541) 737-8008 or by email at IRB@oregonstate.edu

11. WHAT DOES MY COMPLETING & SUBMITTING THE ATTACHED SURVEY MEAN?

By proceeding to and completing the following survey, I acknowledge that I have read and understand the Informed Consent Form listed above. My signature is not required to verify this as signing will identify me with my responses. My completion and submission of the following survey is my stated consent and verification.
QUESTIONNAIRE

SECTION 1: INJURY SPECIFICS

I am a:

Male  Female

Between the ages of:

18-19
20-22
23-25
25-30
30-35
35-40
40-45
45-50
50-55
55-60
60+

My injury occurred this long ago:

____ years
____ months

I was injured in this area (check all that apply):

____ Left/Right frontal lobe
____ Left/Right temporal lobe
____ Left/Right parietal lobe
____ Occipital lobe
____ Midbrain
____ Other (please explain in box provided)

How were you injured?

____ Interpersonal violence/Abuse/Domestic Violence
____ Fall
____ Sports
____ Motor Vehicle Accident (collision)
____ Motorcycle Accident
____ Bicycle Accident
____ External Impact (being struck by an object)
____ Firearm/Blast impact
____ Other (please explain on the lines to the right)
Did you receive therapy in the hospital? Check all that apply:

- Occupational
- Speech
- Recreational
- Physical
- Cognitive
- Psychological
- Other (please explain)

Did you continue to receive therapy once you had left the hospital? Check all that apply:

- Occupational
- Speech
- Recreational
- Physical
- Cognitive
- Psychological
- Other (please explain)

We are very interested in your opinions of the therapy you received. This section asks you general questions about your experiences with medical staff and how you felt during your time in the hospital and at home.

In addition to the available options, a space is left for you to elaborate on your responses. We greatly appreciate you sharing specific feelings or experiences, but try to think of the entire time you spent with medical personnel and make your responses represent a summary of your whole experience.

Please respond to each of the following questions by checking the box next to the response that most closely fits how you feel regarding that question. Please try to respond to each item separately in your mind from each other item. Although you may skip any question if you feel uncomfortable thinking about the topic or sharing your response, please answer as many as you are able.

Which therapy do you think you received the most benefit from?

- Occupational
- Speech
- Recreational
- Physical
- Cognitive
- Psychological
- Other (please explain)
Which therapy did you like the most?

___ Occupational
___ Speech
___ Recreational
___ Physical
___ Cognitive
___ Psychological
___ Other (please explain)

Why did you like it more than others?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Which therapy did you dislike? (mark all that apply)

___ Occupational
___ Speech
___ Recreational
___ Physical
___ Cognitive
___ Psychological
___ Other (please explain)

Why did you dislike that therapy?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Did you feel your therapists treated you with respect?

___ I always felt treated with respect.
___ Most of the time I felt treated with respect.
___ Sometimes I felt treated with respect.
___ Undecided, I felt neither respect or disrespected.
___ Sometimes I felt I was treated with disrespect.
___ Most of the time I felt disrespected.
___ I always felt disrespected.

Did you feel more or less respected by a particular therapist, or by all of your therapists?

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

Is there something that stands out to you as far as respect is concerned?

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

How did your therapists make you feel while they were helping you with therapy?

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________
Did you get along well with your therapists?

_____ I always got along well with my therapists.
_____ Most of the time I got along well with my therapists.
_____ Sometimes I got along well with my therapists.
_____ Undecided, I didn’t have much of a personal relationship with my therapists.
_____ Sometimes I did not get along well with my therapists.
_____ Most of the time I did not get along well with my therapists.
_____ I never got along with my therapists.

Outside of helping you complete therapy, did you have a good personal relationship with your therapists?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Would you change any of the therapy that you received? Please tell us which therapy you think needs to be changed.

_____ Occupational
_____ Speech
_____ Recreational
_____ Physical
_____ Cognitive
_____ Psychological
_____ Other (please state which therapy you think needs to be changed)
Do you think that if the therapy you received was different you would have healed more successfully?

   ____________
   ____________
   ____________
   ____________
   ____________
   ____________
   ____________

   __________________________
   __________________________
   __________________________
   __________________________
   __________________________
   __________________________

   What changes do you suggest?

   __________________________
   __________________________
   __________________________
   __________________________
   __________________________
   __________________________

   Why do you feel these changes need to be made?

   __________________________
   __________________________
   __________________________
   __________________________
   __________________________
   __________________________

   Do you have any ideas for new therapy methods that you think would benefit other people who have experienced a traumatic brain injury?

   __________________________
   __________________________
   __________________________
   __________________________
   __________________________
   __________________________
As far as your experience in the hospital goes, how did you feel during that time?
(We have provided a list of emotions for you to review to help you put your feelings into words.)

You DO NOT need to respond to the whole list, the list is merely given to spark your ideas.

Please circle a frequency and feel free to comment on any emotion listed that you believe best represents how you feel IN GENERAL today and if any of these emotions have shifted since your injury.

If you have any other comments to add, space is provided below the emotion list.

Typically, I feel:

Affectionate, Loving, Caring
very faintly a little somewhat clearly strongly very strongly

Amused, Having fun
very faintly a little somewhat clearly strongly very strongly

Angry, Irritable, Frustrated
very faintly a little somewhat clearly strongly very strongly

Anxious, Nervous
very faintly a little somewhat clearly strongly very strongly

Compassionate
very faintly a little somewhat clearly strongly very strongly

Sympathetic
very faintly a little somewhat clearly strongly very strongly
Grateful, Appreciative, Thankful
very faintly  a little  somewhat  clearly  strongly  very strongly

Happy, Pleased, Joyful
very faintly  a little  somewhat  clearly  strongly  very strongly

Sad, Depressed, Down
very faintly  a little  somewhat  clearly  strongly  very strongly

Cared about, Loved, Connected
very faintly  a little  somewhat  clearly  strongly  very strongly

Interested, Attentive
very faintly  a little  somewhat  clearly  strongly  very strongly

Uninterested, Uninvolved
very faintly  a little  somewhat  clearly  strongly  very strongly

Lonely, Isolated
very faintly  a little  somewhat  clearly  strongly  very strongly

Proud, Good about myself
very faintly  a little  somewhat  clearly  strongly  very strongly

Relaxed, Calm
very faintly  a little  somewhat  clearly  strongly  very strongly

Delighted, Pleased
very faintly  a little  somewhat  clearly  strongly  very strongly

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Physically uncomfortable, Not at ease
very faintly a little somewhat clearly strongly very strongly

Ashamed, Embarrassed, Humiliated, Disgraced
very faintly a little somewhat clearly strongly very strongly

Hopeful, Optimistic, Encouraged
very faintly a little somewhat clearly strongly very strongly

Guilty, Blameworthy
very faintly a little somewhat clearly strongly very strongly

If you have any comments to offer about how you typically feel, please offer them below.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

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For the following questions, please go along fairly quickly and mark the answer that first comes to mind. 

Please mark the response that best represents your agreement or disagreement with each statement.

In general, I feel I am in charge of the situation in which I live.  

___ Disagree strongly  
___ Disagree a little  
___ Neither agree nor disagree  
___ Agree a little  
___ Agree strongly

The demands of everyday life often get me down.  

___ Disagree strongly  
___ Disagree a little  
___ Neither agree nor disagree  
___ Agree a little  
___ Agree strongly

I do not fit very well with the people and the community around me.  

___ Disagree strongly  
___ Disagree a little  
___ Neither agree nor disagree  
___ Agree a little  
___ Agree strongly

I am quite good at managing the many responsibilities of my daily life  

___ Disagree strongly  
___ Disagree a little  
___ Neither agree nor disagree  
___ Agree a little  
___ Agree strongly

I often feel overwhelmed by my responsibilities.  

___ Disagree strongly  
___ Disagree a little  
___ Neither agree nor disagree  
___ Agree a little  
___ Agree strongly
If I were unhappy with my living situation, I would take effective steps to change it.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I generally do a good job of taking care of my personal finances and affairs.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I find it stressful that I can’t keep up with all of the things I have to do each day.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I am good at juggling my time so that I can fit everything in that needs to get done.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

My daily life is busy, but I derive a sense of satisfaction from keeping up with everything.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly
I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

My efforts to find the kinds of activities and relationships that I need have been quite successful.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I have difficulty arranging my life in a way that is satisfying to me.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I have been able to build a home and a lifestyle for myself that is much to my liking.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

I feel confident that I can learn to cope with the stressors in my life.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly
If I want to, I can change the way I cope with stress.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

No matter how hard I try, I can’t really change the way I cope with stress.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

The truth is, I have very little control over how I cope with the stressors in my life.

___ Disagree strongly
___ Disagree a little
___ Neither agree nor disagree
___ Agree a little
___ Agree strongly

The following questions ask you about your feelings and thoughts during the last month. For each question, please circle how often you felt or thought a certain way.

In the last month, how often have you been upset because of something that happened unexpectedly?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you felt that you were unable to control the important things in your life?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you felt nervous and “stressed”?

Never  Almost Never  Sometimes  Fairly often  Very often
In the last month, how often have you felt confident about your ability to handle your personal problems?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you felt that things were going your way?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you found that you could not cope with all the things that you had to do?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you been able to control irritations in your life?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you felt that you were on top of things?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you been angered because of things that were outside of your control?

Never  Almost Never  Sometimes  Fairly often  Very often

In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Never  Almost Never  Sometimes  Fairly often  Very often

If you have any additional comments about this or any part of the survey, please share them here:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

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