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# The Effects of Traumatic Brain Injury on Families

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THE EFFECTS OF TRAUMATIC BRAIN INJURY ON FAMILIES

by

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B.S., Southern Illinois University, Edwardsville, 2012

A Research Paper

Submitted in Partial Fulfillment of the Requirements for the  
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Rehabilitation Institute  
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RESEARCH PAPER APPROVAL

THE EFFECTS OF TRAUMATIC BRAIN INJURY ON FAMILIES

By  
Annie M. DeBaillie

A Research Paper Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of  
Master of Science  
in the field of Rehabilitation Counseling

Approved by:  
Dr. Jane L. Nichols

Graduate School  
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AN ABSTRACT OF THE RESEARCH PAPER OF

ANNIE M. DEBAILLIE, for the Master of Science degree in REHABILITATION COUNSELING, presented on JUNE 30, 2014, at Southern Illinois University Carbondale.

TITLE: THE EFFECTS OF TRAUMATIC BRAIN INJURY ON FAMILIES

MAJOR PROFESSOR: Dr. Jane L. Nichols

For individuals who sustain a traumatic brain injury (TBI), the disabling effects can greatly impact their life. The effects of a TBI can include physical, emotional, and cognitive impairments that can impact their ability to function in their everyday lives. The recovery process following a TBI can be extensive and costly. Many times the burden of the care and cost falls on the family of the individual with a TBI. Caring for the family member with a TBI can cause a disruption in the function of the family. This disruption can cause stress, anxiety, and burden within the family caregivers.

This paper reviews literature related to TBI, the impact TBI has on family caregivers, and a theoretical family system model that addresses family and marital systems. Three areas will be addressed. Chapter one discusses TBI focusing on incidence, financial assistance, access to services, and the impact on families. Chapter two presents a literature review of current research regarding the effects of TBI on the family system, a review of the Circumplex Model of Marital and Family Systems and how it pertains to families with TBI, and how rehabilitation counselors can use this theoretical framework to work with families with TBI. Chapter three provides a discussion and recommendations for future research.

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## CHAPTER 1

An individual with a traumatic brain injury (TBI) can have long-term physical, psychosocial, and cognitive deficits that affect the individual's emotional, interpersonal, and vocational functioning (Kosciulek, 1994). Many times the responsibility of meeting these needs falls on the individual's family. The impact of meeting the needs of the individual can affect the entire family system emotionally, personally, financially, and socially. With the difficulties the family may be facing they may try to access services to help lessen the strain, but individuals with a TBI and their families may come across barriers to accessing these services. Barriers may include a lack of accurate diagnosis or any diagnosis applicable to a brain injury, a lack of insurance to access critical services, a shortage of trained providers close to the family, prolonged unemployment for the individual with a TBI, and challenges navigating the complex service and support infrastructure (Strickland, 2012).

This paper is an investigation of how a TBI affects the family system, what approaches are empirically based to help the family, and what interventions are available to families of individuals with TBI. Rehabilitation professionals should aim to promote "family-centered" care to increase the involvement of family in the treatment, to bring awareness of the effects TBI has on the family, and to promote the integration of services for families.

### **Background of the Problem**

A TBI is an important health concern in the United States. On average, at least 1.7 million Americans experience a TBI each year, which means that someone sustains a brain injury every 19 seconds (Stickland, 2012). A TBI can be defined as acquired damage to the brain that results when the head is hit, strikes a stationary object or is shaken violently (Noble, Laski, Conley, & Noble, 1990). The causes of TBI are very diverse. They can range from car accidents, falls, or



from firearms. A TBI can happen to anyone at any stage of life. With the number of fatalities associated with TBI dropping, there has been a significant increase in the number of survivors with TBI who can benefit from recent advances in the fields of medicine and technology.

Individuals surviving TBI may experience serious long-term consequences and substantial costs associated with it (Tiesman, Konda, & Bell, 2011). Long-term effects may include cognitive, physical, and emotional deficits. Cognitive deficits may include memory loss, concentration issues, or have a hard time problem solving. Physical deficits may include not being able to shower or get dressed independently, hearing and visual impairments, and sensory-motor deficits that affect the ability to smell and taste. Emotional deficits may be one of the hardest and most disabling deficits; which may impact relationships with others, the ability to return to school or work, or to live independently. (Kosciulek, 1994). Some behavior changes may include aggression, which is a long established neurobehavioral outcome of a TBI. The impact of anger and aggression can be devastating for individuals with TBI and their families (Dyer, Bell, McCann, & Rauch, 2006). With physical, cognitive, and emotional deficits it is hard for an individual with a TBI to return to work. Gainful employment is one of the domains that is significantly affected following a TBI. Not being able to go to work has financial implications such as a lack of financial independence, health care coverage and providing for dependents. Along with the financial implications, obtaining and maintaining employment is strongly related to the quality of life and the well-being of an individual (Tsaousides, Warshowsky, Ashman, Cantor, Spielman & Gordon, 2009).

Financial assistance for caregivers who lack insurance coverage may come from federal government programs, state and local government programs, community groups, religious organizations, or not-for-profit organizations. Federal government programs include

Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). These federal government programs help individuals with disabilities that have no or little income pay for food, clothing, and a place to live (Brain Injury Association of America, 2014). State government programs include the Department of Human Services that assists individuals and their families reach their employment, independent living, and educational goals. Along with the state government program, the Human Resources and Services Administration (HRSA) was charged with implementing a grants program to State and American Indian Consortia to improve access to rehabilitation. The resulting 2008 Traumatic Brain Injury Act amended the 1996 Public Law (P.L.) 104-166 that was “to provide for the conduct of expanded studies and the establishment of innovative programs with respect to [TBI]” (Strickland, 2012, p. 3). While funding resources are available, not everyone who sustains a brain injury is eligible to receive financial assistance. Reasons for eligibility range from severity of the injury and limits of funding in the geographic location where the caregiver resides. Waiting times for waiver services, lasting an average of 25 months for individuals reliant on Medicaid, prevent individuals from receiving services when they would be most effective. In addition, the structure of the post-acute service delivery system (referral, discharge, treatment planning, and education) is fragmented, making it difficult to obtain information about funding and services for TBI (Pickelsimer, Selassie, Sample, Heinemann, Gu & Veldheer (2007).

Alban and colleagues (2010) found that TBI patients with severe injuries and insurance have improved outcomes compared to patients without insurance. Caregivers of individuals with TBI should examine their policy closely for time limits, benefit limits and exclusions. Typically, insurance policies are geared toward wellness and routine health care versus acute, post-acute care, and rehabilitation. Some insurance companies are required by state law to provide long-

term coverage for TBI, but not every state requires this. Dependent on coverage, a health insurance policy may pay for all of the medical care during the acute stage of recovery; however, the recovery process can last for many years and usually requires caregivers and individuals with the TBI to have access to services in their home and community beyond the acute phase of recovery. The recovery process for many takes extensive rehabilitation. Extensive rehabilitation may include physical, occupational, speech, and neuropsychological therapy, plus cognitive rehabilitation. Health care insurers may put a limit on what they pay for in both inpatient and outpatient rehabilitation. Inpatient rehabilitation may be limited or outpatient rehabilitation insurers may be capped at a certain number of reimbursable sessions (Prowe, 2010).

These effects of a TBI do not only affect the person with the TBI; they affect the individual's family caregiver. Once a family member sustains a TBI a family caregiver is thrust into a multiplicity of roles: student; medical decision-maker; ancillary caregiver; researcher; psychologist; advocate for their child and family; and teacher/interpreter for family, friends, and the community at large (Rosigno & Swanson, 2011). A family caregiver is an unpaid family member who provides care to an individual who needs assistance in a variety of tasks.

According to the National Alliance for Caregiving (2004), there is an estimate of 44 million family caregivers that are over the age of 18 years old who provide sole care for persons with TBI. This is approximately one in five adults in the US. Further, the economic value of their unpaid work is estimated at \$257 billion dollars (Reinhard, Given, Petlick & Bemis, 2008).

Family members may leave their paid careers to help and care for the family member with a TBI. Supports available to families with individuals with TBI vary according to location. National organizations such as the Brain Injury Association of America and the Center for Head Injury Services are available to help families learn about TBI and to help locate services. However, in

rural areas these services are few if any exist at all. A family caregiver may have to find these resources themselves due to the lack of education among providers regarding the social and psychological consequences of TBI. Effective discharge planning is not possible without this knowledge. Some families have reported that providers are not looking at the long term and are premature in deciding what opportunities or resources are warranted for their family member, based on a medical or statistical perspective (Roscingo & Swanson, 2011).

An extensive amount of literature provides firm evidence that head injury hurts families emotionally, socially, and financially (Kosciulek, 1994). With the assumption of new roles and demands, family caregivers may experience feelings of depression, anger, and denial, which cause disturbances in the family functioning. Such literature has shown that over time families become isolated, financial burdens become unmanageable, and the emotional and psychological functioning of family members takes a significant toll. When an individual in the family sustains a TBI, the impact of the TBI may be as great for the family as it is for the individual with the TBI. Immediately following the TBI family members may experience shock, denial, disbelief, burden, or anger. Anxiety and stress are also seen in families after the injury, and symptoms appear to increase for at least up to one year (Kosciulek, 1994). As roles in the family system start to change due to the TBI, problems arise with relationships and the role functioning. As time passes, more problems start such as depression, poor communication, and drug and/or alcohol abuse within the family system (Kosciulek, 1994). Caregivers may also feel unprepared to provide care for their family member with a TBI and they may not receive adequate knowledge from health care providers. Due to inadequate knowledge and skills, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed. There is also a considerable lack of knowledge about what services are beneficial, what services are available in

the community, and how to access these services. Providers, individuals with TBI, and their family members report not having enough knowledge and not receiving enough education about available community services (Corrigan, Whiteneck & Mellick, 2004). As the situation changes, caregivers must seek out and apply for services on their own. Without support from agencies, providers or other groups, this can be difficult if not impossible.

With caregivers being unaware and unprepared may result in caregivers neglect of their own health needs in order to assist their family member, causing deterioration in the caregiver's health and well-being (Reinhard, Given, Petlick, & Bemis, 2008). When looking at the effects a TBI has on specific family members it is important to remember that the TBI impact may differ from one family member to another. Clinical evidence suggests that wives of men that sustain a TBI have a greater amount of difficulties with the impact of the disability than other family members do (Florian & Katz, 1991). Having to take on the main role of the household, wives may experience emotional responses including irritability, depression, frustration, anger, loneliness, and isolation. They may find a decline in their social activities, and a lack of economic security resulting from less personal time (Florian & Katz, 1991). Parents may be responsible for their child with a TBI for the rest of their lives and may never experience the independence or freedom they anticipated having in their later years of life (Florian & Katz, 1991). Florian & Katz (1991) found that dependency is a natural part of the relationships between parents and their children. This quality of the parent/child relationship may help parents more than other family members in accepting changes in their child. Even though parents can accept behavior changes, they may have more unrealistic expectations of improvement for the individual with a TBI and have a harder time dealing with lack of improvement or setbacks.

There has been little research done on the impact of a parent's TBI on the psychosocial functioning of their children. Some studies have shown that children may feel that they need to behave like adults to compensate for the parent with a disability; these children may suppress their feeling in front of others and feel a sense of loneliness, guilt, or anger. Other children with a parent with a TBI may respond by acting out, withdrawing from others, or using drugs and/or alcohol (Florian & Katz, 1991). Lezak (1978) found that many husbands with TBI not only failed to assume any responsibility for their children, but they often competed with their children for attention and love from their wives. If a parent with a TBI displays aggressive or unusual behavior, a child may not feel comfortable bringing their friends home. This may cause the child to feel neglected and abandoned by their parents. The experience for a child may cause them to develop a loyalty solely for the healthy parent. Children of parents with TBI face multiple difficulties in adaptation; therefore, they may also be considered additional victims of TBI and should receive additional attention from rehabilitation professionals (Florian & Katz, 1991).

### **Significance of the Study**

Rehabilitation professionals encounter individuals with a TBI frequently and need to understand the importance of how a TBI affects the family dynamic and how to help the family in the rehabilitation process. When an individual sustains a TBI, much of the responsibility for the support of that person lies within the informal family caregiver who usually is a family member or a spouse. Consideration of the needs of those individuals filling the family caregiver role is essential, given that 80% of adults who survive TBI return to the community and need help from their family for support and care (Albert, Im, Brenner, Smith & Waxman, 2002). With the support and care of their family members, individuals with TBI can have an improved recovery. The speed of recovery for the individual with TBI has been closely related with the

health, stress level, and psychological burden of the primary family caregiver. (O'Callaghan, McAllister, Wilson, 2011).

This paper will explore strategies that have been shown to be effective in improving family functioning in identifying family stressors and how they successfully cope with a family member with a TBI. Family adaption to a head injury is largely influenced by family efforts to maintain a positive attitude and have a realistic outlook toward their family and the individual with a TBI's situation (Kosciulek, 1994). Helping families cope by directing them to available resources and supports, will benefit both the individual with TBI as well as the family. Rehabilitation professionals can use this information to better prepare themselves to work with a client and their family. This paper is a comprehensive literature review of strategies that have been proven to help families cope with a family member with a TBI. Therefore, this research paper has a focus on the importance of families with TBI to have improved family functioning.

### **Purpose and Objectives of the Paper**

The purpose of this study is to bring awareness to the effects a TBI has on the family system and to review literature of what models rehabilitation counselors can use to help families keep a balanced system. Families with balanced system types will generally function more adequately across the family life cycle than unbalanced families (Gorall & Olson, 1995). During the beginning stages of rehabilitation, studies have shown that family caregivers of individuals with a TBI first need realistic, clear, and regular information regarding their family member's prognosis, treatment, and current status. Short and long-term needs include information, instrumental, professional support, respite, caregiver training, and emotional support. Unfortunately, these areas are frequently unmet (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). Making the effort to help the family early in the recovery process and providing ongoing

support can in return help the individual with the TBI recover and help the substantial costs by informing the families of support services available and giving them the education, they need on a TBI. Many families report that the most painful aspects of the injury are due to the lack of accurate information available to them at all points following the injury and the fact that a TBI's effects are very different from other illness and injuries (Deaton, 1986). When professionals take the time to listen empathically, with a willingness to re-explain as necessary an improved therapeutic alliance will be formed with caregivers/ families (Roscigno & Swanson, 2011). Providing this advice with specific understanding of the family's needs is crucial. Examples of model interventions and the rehabilitation counselor's roles in understanding the family's needs will be supported by an analysis of the available literature. A final chapter discussing suggestions for future research, as well as implications and conclusions that can be drawn and applied to counseling practice will follow.



## CHAPTER 2

### LITERATURE REVIEW

TBI results in physical, cognitive, and emotional symptoms. These symptoms can influence a person's ability to accomplish everyday tasks, have satisfying interpersonal relationships, and to be able to participate in the community. To understand the impact of TBI on the individual and their family it is important to understand the course of the treatment process.

#### **Treatment Process**

At the time of injury, the individual with TBI will be assessed at a medical center or hospital to determine the next steps for care. This may involve surgery, other medical interventions or palliative care. Often the individual with TBI will be in a comatose state for hours, days or weeks. If the TBI is significant, they will typically be admitted to intensive care and then to a trauma or specialized care unit. At the specialized care unit, an assessment would be made regarding the medical and rehabilitation issues related to the TBI and other injuries. The specialized care unit will also work to restore lost functional abilities, such as the ability to talk, eat, think, or move. Length of stay in post trauma care can be days or months depending on the severity of the injury. Long-term care including speech therapy, physical therapy, psychiatry, occupational therapy and rehabilitation counseling is provided in outpatient or inpatient settings. During this entire process, the family is required to interact with multiple medical and related health care practitioners. They may be arranging time off at the individual's workplace, addressing insurance needs, juggling their own jobs, childcare, school and the like. In addition, they are anticipating being the primary caregiver for the individual with TBI who may be an

entirely different person than the one that they once knew. Clearly, the family is under significant stress at this time.

On homecoming, the family and the family member with TBI must adapt considerably. Psychosocial functioning is usually affected even in cases of mild TBI (Nichols & Kosciulek, 2014). In order to maintain good psychosocial functioning interactions between the individual with a TBI and their family external factors is critical. External factors may include the environment, the ability to access services, and the level of social support (Yi & Dams-O'Connor, 2013).

### **Environment**

The environment can include physical barriers such as buildings, stairs, doorways, and even the weather. Other environmental factors that influence psychosocial function include a lack of transportation, government policies, and attitudes of others. Attitudinal barriers consist of negative attitudes and prejudice against individuals with TBI. When the public is unaware of the effects, symptoms, and the recovery process; misconceptions are made. Some misconceptions may include believing that recovery depends on the individual with a TBI's efforts or that a person with a severe brain injury may completely recover with only some memory problems (Gouvier, Prestholdt & Warner, 1988). These misconceptions can leave individuals with TBI and family caregivers with unrealistic hopes and increased frustration. TBI is an invisible disability, in that a person's appearance does not show that they have an injury. This invisibility can increase stigma and a lack of understanding for appropriate services. Misconceptions can also lead to inappropriate rehabilitation strategies as well as incorrect legal actions regarding the effects of TBI (McClure, 2011). In order to access services there are rules and regulations set up by policy makers and from government rules. The TBI Act of 1996 allowed the U.S. Department

of Health and Human services to assist in prevention, education for the public and to conduct research. The act also helped states with grants to develop and expand services as well as to help protect the rights of individuals with TBI (Brain Injury Association of America, 2014).

However, there is still a need to educate society on the presence of TBI as a chronic condition that needs qualified professionals and evidence-based treatment. Community integration and supports that are individualized to help with education, employment, transportation, socialization, or recreation for individuals with TBI still require advocacy.

### **Access to Services**

Many individuals and families affected by TBI have a difficult time negotiating the medical, mental health and vocational systems to obtain appropriate care. Some environmental barriers exist for many persons with disabilities; however, some environmental and emotional barriers are peculiar to those who have sustained a TBI. Meixner and colleagues (2013) identify the following barriers to care for those with TBI, and their caregivers:

- Misdiagnosis or no diagnosis
- Limited or no public transportation in rural locations
- Limited sources of funding for services
- Limited if any long term case management
- Family education on course of the disease
- Stigma
- Organizational barriers-
  - Poorly defined eligibility criterion
  - Inappropriate treatment plans
  - Practitioner lack of knowledge related to TBI

- Paucity of appropriate and acceptable, age related services

An absence or lack of access to services has negative impacts on the family member with a TBI as well as the family caregivers. To the degree of which services and support needs are met after a TBI has a significant impact on the long-term outcomes for the individual and the family (Turner, Fleming, Ownsworth & Cornwell, 2011).

### **Mental Health**

If an individual with a TBI needs psychiatric care, barriers also exist. Once discharged from the trauma hospital it is difficult to access services, and the mental health issues may persist for years after being discharged. In individuals with TBI, 77% experience depression (Meixner, O'Donoghue & Witt, 2013). Depression may result from an individual's perception of their functioning as well as from problems adjusting back into the community. If mental health issues are left untreated, the risk of suicide increases. Providers should be aware of possible psychiatric symptoms because many times individuals will seek treatment for medical concerns and do not disclose any mental health problems (Meixner, O'Donoghue, & Witt, 2013)

### **Social Support**

TBI physical and functional symptoms tend to diminish during the first years post-injury, but social and psychological issues will remain present (Izaute, Durozard, Aldigier, Teissedre, Perreve & Gerbaud, 2008). These lingering side effects can affect the individual's life tremendously. If social support is available, it can help the individual have better outcomes and adaptation into the community. "Social support is usually defined as the existence and availability of people on whom one can rely and who provide care" (Izaute, Durozard, Aldigier, Teissedre, Perreve & Gerbaud 2008, p. 759). Many times after a TBI, individuals will experience a

decrease in their social support system. This may be due to their inability to return to work and to other social functions that they were able to attend prior to a TBI.

### **Adults**

Receiving a TBI during adulthood can affect the individual differently than a TBI sustained during childhood. The main cause of TBI in older adults is attributed to falls (Yi & Dams-O'Connor, 2013). When an adult sustains a TBI there may be changes in the function and structure of the brain as well as an increase of co-morbid health conditions. Age-related conditions such as arthritis can reduce mobility and cause an increase for re-injury (Yi & Dams-O'Connor, 2013). These other medical conditions may make treating the symptoms of the TBI more difficult. Many times adulthood is a time to reflect upon their life experiences and sustaining a TBI may interrupt or delay individuals from obtaining such milestones they anticipated having. When an individual is unable to return to work, it may limit their level of social interaction and increase social isolation. Adjusting to life after a TBI is a long-term process that is impacted by environmental factors, such as not being able to return to work, social support, and the physical environment of their home. Pre-injury coping strategies, personality traits, and characteristics of the injury can all impact adjustment to TBI as well, in both positive and negative ways. When treating an older individual with a TBI it is important to remember that they do not have the same internal and external factors influencing their functioning as younger adults. Internal factors affecting older adults may consist of their knowledge regarding TBI, their attitude, beliefs, core values, social life, adaption skills, self-efficacy, and psychiatric conditions such as anxiety or depression. External factors affecting an older individual with a TBI include social supports, sociocultural, economic, and political factors, environmental stressors, and biologic or preexisting medical conditions (Cole, Holtgrave & Rios, 2008).

## **Children**

TBI in children can result in serious consequences, ranging from cognitive deficits, long-term disability, or even death. Other issues many result in physical disabilities, social skill deficits, problems in school performance, and behavioral issues (Yeates, Taylor, Walz, Stancin & Wade, 2010). Childhood is when social and emotional development takes place. During this time of development, friends are made and self-esteem develops. When a child or adolescent has a TBI, it affects the child's ability to make friendships and can cause loneliness and withdrawal from activities.

Other barriers related to the TBI may not even be apparent until later in life. Issues may come up during transitional periods of their life where more relationships that are complex are being built (Ross, McMillan, Kelly, Sumpter & Dorris, 2011). This study confirmed that children who have sustained a TBI have more severe difficulties when it comes to hyperactivity, attentional issues, and emotional problems compared to their non-injured classmates. To help with social skills, cognitive abilities, and emotional well-being, it has been suggested that these children complete cognitive training as part of their rehabilitation and education. Along with cognitive training, the family environment is an important factor in the psychosocial outcomes following a TBI. Yeates and colleagues (2010) found that eighteen months after a TBI, families who had adjusted to the injury well had sustained these improvements over time.

## **Family**

Many factors influence psychosocial functioning in individuals with TBI. Many of the same factors influence the family as well. Family caregivers may experience psychosocial distress such as stress and depression (Man, Lam, & Bard, 2003). The stressors may be associated with the behavioral and cognitive impairments of the family member with TBI, such

as anger, impaired attention, and reduced memory (Simpson & Jones, 2012). Other reasons behind caregiver distress may be due to the variety of complex, stressful, and time-consuming tasks to help their family member recover. The caregivers may experience disturbances in their employment, social isolation, financial difficulties, family adjustment, and poor quality of life due to the tasks required in the recovery process (Lehan, Stevens, Arango-Lasprilla, Sosa & Jove, 2012).

Family caregivers also experience unmet service and support needs. Gan and colleagues (2010) found when observing the common needs among families who are coping with TBI, there were five interconnected themes identified; coping, barriers, supports needed, supports that worked and recommendations. In regards to coping, family caregivers struggled to manage the symptoms of TBI. Along with struggling with the symptoms of TBI, the caregivers experience isolation socially and emotionally in their caregiving responsibilities. Barriers to accessing services and their needs include stigma, a lack of understanding, a lack of availability of services, funding resources, and their geographic location (Turner, Fleming, Ownsworth, & Cornwell, 2011). Formal and informal supports are needed for the entire family to help with coping and the responsibilities of caregiving. Formal supports include government and private agencies that are set up to assist individuals and families. Formal supports can also be medical centers, volunteer organization, churches, or mental health centers. Informal or natural supports for families include other family members, friends, neighbors, or other caring and knowledgeable individuals who know the family and the family member with the TBI (Simon, Kumar, & Kendrick, 2008). To help obtain the supports needed, it is important to educate and enhance awareness of employers, employees, schools, health care providers, and insurance companies (Gan et al., 2010). To help family caregivers there is a need for continued support for the individual with TBI, caregiver

support, family counseling, clear information and education for family caregivers, and services that are more accessible.

### **Circumplex Model**

In order for counselors to help families, it is essential to be familiar with a model that will provide a guide to serve this population. A very useful model is the Circumplex Model of Family Systems. This model has been widely used in the clinical and academic settings (Yahav, 2002). The model was first developed by Olson, Spink, and Russell in 1979 to be used by counselors to diagnose where the problems lie within the family system (Maynard & Olson, 1987). It is system-focused and integrates three dimensions that are considered highly relevant within other family therapy models and therapy approaches. The three dimensions of the model are *family cohesion*, *flexibility*, and *communication*.

The main hypothesis of the Circumplex Model is that balanced families and marital couple types are more likely function in healthier ways than unbalanced family and couple of types. The model and its assessment instruments are used for treatment planning, clinical assessment, and interpreting research outcomes on the effectiveness of family and marital therapies (Olson, 2000).

### **Cohesion**

Marital and family cohesion is defined by Olson (2000, p. 145) “as the emotional bonding that family members have towards one another.” Looking at marital and family cohesion can help a counselor diagnose and measure how the family balances itself. There are four levels of cohesion; disengaged, separated, connected, and enmeshed. They range from very low (disengaged) to very high (enmeshed).



A balanced family fits into the separated and connected levels of cohesion. The families in these areas are able to be both independent of each other as well as be connecting with the family. A couple and family system in the balanced category are least likely to seek therapy. They tend to be more functional across the life cycle. Separated relationships tend to emphasize apart time, but there is still time together, marital support, and joint decision-making. Connected relationships have more emotional closeness, and time together is more important than the time spent apart. When family behavior falls in the extreme or unbalanced levels, they are usually problematic. These types of families are the ones usually seeking therapy. When families have high cohesion behaviors or are much enmeshed, little independence and too much consensus is frequently observed. On the other hand, families whose members tend to do what pleases them with little thought of the family unit may be perceived as having little commitment to their own family.

Families who demonstrate behaviors suggesting that disengaged relationships exist, will demonstrate extreme emotional disconnectedness; each member of the family is very independent and is unable to another for support. An enmeshed relationship has an emphasis on extreme togetherness and closeness. Individuals in this type of relationship are very dependent on each other and there is very little personal space. There is no perfect level for any relationship or family, but if one stays in one extreme end for too long, problems will arise (Olson, 2000).

### **Flexibility**

The next dimension of the Circumplex Model of Family Systems is marital and family flexibility. Flexibility is “the amount of change in its leadership, role relationships and relationship rules” (Olsen, 2000, p. 147), as applied to relationships, negotiation styles, and leadership. The flexibility of the dimension measures how systems balance constancy versus

adjustment. There are four levels of flexibility; rigid, structured, flexible, and chaotic. These levels vary from very low (rigid) to very high (chaotic). The structured and flexible levels within families are seen as more balanced. Rigid and chaotic levels are seen as being more problematic for families. Families and couples both need stability and change in their relationship. When a family or couple is unable to change when appropriate, it distinguishes themselves from the functional couples or families. A structured relationship will have a democratic leadership with some negotiation. The rules of this relationship will constant with some sharing involved. Flexible relationships consist of an egalitarian leadership with a democratic approach to the decision-making. The roles are shared, rules can be changed, and negotiations are open to the whole family. With these two types, the family system tends to become more functional over the life cycle. A rigid or chaotic family or couple tends to be unbalanced. One person in the family being in charge of all decisions with no decision making by their family members exemplifies rigid relationships. A chaotic relationship comprises of an absence of leadership and decisions that are made on impulsive and are not thought out (Olson, 2000).

### **Communication**

The third dimension of the model is communication and is considered the facilitation dimension. This dimension helps facilitate movement within the other two dimensions. Family and couple communication is measured by their speaking and listening skills, respect and regard, self-disclosure, staying on topic, and clarity. Balanced families and couples tend to have good communication versus unbalanced families tend to have a lack of communication (Olson, 2000). Positive and negative communication can move families from one level of cohesion and/or adaptation. Communication is a main factor involved in family

system change and must be evident, and conjointly with the other dimensions (Gorall & Olson, 1995).

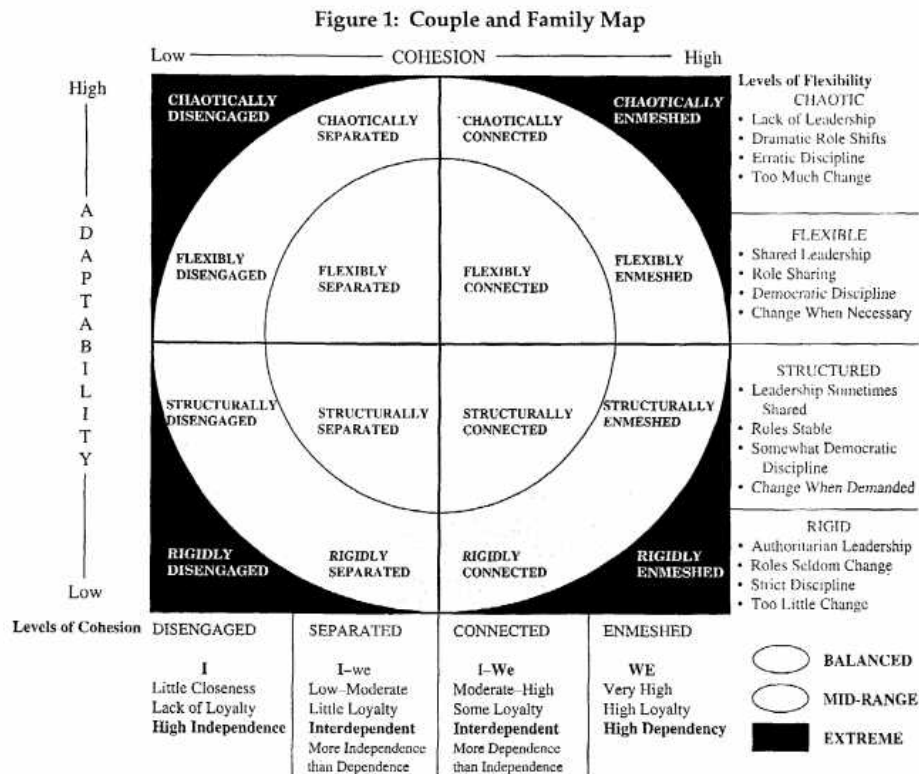


Figure 1: Circumplex Model: Couple and family map (Olsen, 2000).

### Assessment Tools

To evaluate cohesion and flexibility, self-report and rating scales were developed.

To measure cohesion and adaptability within families a self-report instrument the Family Adaptation and Coping Evaluation Scales (FACES) was developed by Olson, Portner, and Bell in 1978 and later produced FACES II and FACES III. FACES II assesses how family members currently perceive their family and how they would ideally like their family to be. A family member will rate using a five-point scale from almost never to almost always (Maynard & Olsen, 1987). From the findings of the FACES studies, a three-dimensional version of the Circumplex

Model was founded. The new model integrated all the findings from the FACES; high scores were representative of balanced systems, while low scores reflected unbalanced systems. The new model is more empirically and conceptually relatable to other family models and it can incorporate first and second order change. First-order change relates to the flexibility dimension, when there is too much or too little change there is less functional patterns within families. Second-order change is assessed over time, such as in times of stress or in unpredictable changes. When there are times of stress, a balanced family system will change and adapt, while the unbalanced system will not be able to do so. Inability to change creates more stress for the family system. The three-dimensional model also is able to demonstrate the dynamic similarity within the unbalanced and unbalanced types of family systems (Olson, 2000).

### **Circumplex Model and TBI**

The Circumplex Model states that change can occur over time in families and in couples. Change occurs because of developmental changes and situational stress in the life cycle. This includes marriage, pregnancy, raising a child, living as a couple again, or an injury affecting a family member. When change occurs, the family system must then figure out how to deal with that change. Family systems also change due to a crisis in the family. In balanced families, they would shift their resources and skills to cope. Unbalanced families in contrast would not be able to have the resources that they need to change and will have a more difficult time adapting to the crisis. Thus, balanced families have a higher second-order change, due to their family system being able to adapt to a crisis (Olson, 2000). For families with a member who has experienced TBI their family functioning can be negatively affected by personality changes in the person with the TBI and the day-to-day struggles of meeting his or her needs (Kosciulek & Lustig, 1999).

When families view a TBI as a manageable family challenge, they will most likely adapt more successfully than a family that views the TBI as a catastrophe (Kosciulek, 1994).

When using this model with families who have experienced a TBI, it is critical to first reduce any problems and symptoms of the problems. Presenting problems may include behavioral changes in family members, a lack of information, financial burdens, or stress due to caretaking (Kosciulek, 1994). By reducing problems, the aim is to shift the family system into levels that are more balanced. This will help in dealing with stressors associated with TBI from a more manageable approach. The next goal is to work on cohesion or flexibility. This goal is important for families since a serious illness such as TBI may fragment family members, with some not wanting to provide any support or help at all. Counselors can help these families work on the balance between separateness and togetherness or stability and change and get couples/families on the same desire. To facilitate the change in these systems the counselor would work on communication skills so that members of the system can learn how to express their needs, wants, and feelings. A goal of couple and family therapy is to provide families with the necessary skills to negotiate change over time, and not to dwell their current issues. This helps families and couples work toward preventing future concerns (Olson, 2000).

Family plays an important role in promoting a healthy adjustment for a family member with a TBI. TBI can have permanent changes not only in the individual, but as well as in the family system (Gan & Schuller, 2001). All members of the family system are interconnected and a change in one part of the system means that there is change for the whole system (Leaf, 1993). The Circumplex Model can help as a resource for rehabilitation counselors to help determine what type of intervention is the most appropriate and effective with presenting problems and elements of family functioning. It will help families experiencing major stressors, such as a TBI

(Kosciulek, 1996). In regards to family systems and TBI, balanced families function more adequately and have additional positive communication skills than unbalanced families. Understanding family types will assist counselors, researchers, as well as families in extending their information of the most effective adaption strategies following TBI (Kosciulek & Lustig, 1999).

The Circumplex Model is also a valuable tool for treatment planning. It helps in determining the family's current level and functioning style at each of the dimensions. This will help guide the treatment planning to focus on particular components of functioning and have clear and realistic objectives. The main objective of the treatment plan and therapy is to promote patterns that are more functional in the system (Olson, 2000).

This model is sensitive to cultural and ethnic diversity in that it understands that if a families expectations support more extreme patterns, then families will be able to operate if all of the family members agree upon that functional way. It also goes on to state that unbalanced families are not necessarily dysfunctional if they belong to a particular group that has normative extreme behaviors. Counselors assessing families should be aware of the ethnic and cultural heritage. Majority white counselors may see family differences as unbalance when they are functional for other ethnic groups (Olson, 2000). Issues of family structure, ethnicity, and race should be handled with a sensitive and appropriate manner (Gorall & Olson, 1995).

### **Importance to Rehabilitation Counselors and Educators**

Rehabilitation counselors determine whether family rehabilitation is needed and if so, they provide appropriate services to meet the family's needs. From a family's perspective, they are sometimes dissatisfied with the quality of care provided by the rehabilitation counselors (Thomas, Guy, & Ogilvie, 1999). Investigations into the job duties and roles of rehabilitation

counselors found that working with families was not an important aspect of professional practice (Ehrmann & Herbert, 2005). While there has been a gradual increase of awareness of the importance of family involvement to the rehabilitation outcomes for persons with TBI, family counseling skills are still not perceived as a high priority training need by counselors and some educators. A review of rehabilitation counseling training program curriculums, among CORE-accredited programs, revealed that one-third of the programs offered a course on family counseling; one-third offered a partial coursework, while 40 percent of the programs did not offer coursework in family rehabilitation (May & Hunt, 1994). Interestingly, certified rehabilitation counselors employed within state and federal programs perceived family systems education as a high importance training need (Chan et al., 2003). To increase recognition that family rehabilitation is an important aspect of practice, training recommendations include: infusing family concepts into core classes, offering a behavioral family therapy class that emphasizes relationship development, providing a clinical opportunity to work with families, developing a transdisciplinary model to work more effectively with family members, and adopting a conceptual model to increase family involvement into the rehabilitation process (Ehrmann & Herbert, 2005).

Rehabilitation professionals need to pay closer attention to the entire family system instead of just the individual with a TBI. Many times, they are focused on the earlier stages of the recovery process instead of the long-term with the families. During those earlier stages of recovery, families are overloaded with information. Many families did not remember being taught what to expect when the family member was discharged or what resources were available to them (Paterson, Kieloch & Gmiterek, 2001). According to Gan and Schuller (2002) after discharge, many families transition through life changes as they encounter different obstacles in

dealing with the family member with a TBI. During these periods of change the family may experience high levels of stress and adjustment in the families functioning. Rehabilitation professionals should be available and accessible to families during their life changes. When there are supports available for the families during these times, they are better able to negotiate and adapt during these times (Gan & Schuller, 2002). In addition, professionals should understand that upon discharge families are not in the best emotional state at that moment to understand all of the information presented. Rehabilitation professionals should regularly assess the family's understanding of the prognosis, the care being provided, and their future need.



## CHAPTER 3

### DISCUSSION AND IMPLICATIONS

The effects and impacts of TBI on individuals is clearly represented in the literature, but the impact on families is frequently under-estimated (Wells, Dywan, & Dumas, 2005). When the family is not taken into account, it can be problematic because the families are most often the primary caregivers for the family member with TBI. According to Paterson and colleagues, (2001) family members report being frustrated by the lack of information given that will adequately prepare them for life with their family member after discharge from the rehabilitation facility. Caring for a family member with a TBI takes a large toll on the emotional and psychological functioning of the family members (Kosciulek, 1994). This is why intervention techniques should begin immediately after the TBI and continue throughout the rehabilitation process. Gan and colleagues (2010) state that it is critical that services be available as well as accessible to families with TBI across the healthcare continuum: acute, inpatient and outpatient rehabilitation as well as long-term community living. This will help families be better prepared for current and future challenges.

Following a TBI, significant change occurs in the family structure (Curtiss, Klemz, & Vanderploeg, 2000). Family members may experience shock, disbelief, or anger following the occurrence of the TBI. Problems may occur in marital relationships, role functioning within the family, as well as poor physical health of the family caregivers (Kosciulek & Lustig, 1999). Family functioning becomes negatively affected by the strain of meeting the needs of the family member with a TBI.

Theoretically, families are considered interconnected systems. When there is a change in one part of the system, there is going to be change for the system as a whole. This means that the

TBI affects not just the primary family caregiver and the individual with the TBI (Gan & Schuller, 2001), but the experience of TBI affects all members of the family. To help counselors work with families experiencing change The Circumplex Model of Family Systems examines the effects of TBI on the marital or family systems. The Circumplex Model serves as a theoretical framework for counselors to develop family interventions based on family structure (Curtiss, Klemz, & Vanderploeg, 2000). The model is comprised of three key concepts for understanding how a family functions; cohesiveness, flexibility, and communication. The main hypothesis of the model consist of balanced levels of cohesion and flexibility are the most favorable to a healthy family functioning, whereas unbalanced levels of cohesion and flexibility are associated with more problematic family functioning (Olson, 2011). When a family is able to have a balanced and realistic outlook toward the recovery process for TBI, it will help influence how the family adapt new roles and situations (Kosiulek, 1994). Positive attitudes and realistic outlooks are characteristics of a healthy, balanced family. Knowing how the family is functioning and what their family type is, a counselor will be able better prepared to provide effective treatment to the families. Caring for an individual with a TBI can have a number of negative outcomes for the family members including, anxiety, depression, burden, financial difficulties, increase of drugs and alcohol, and poor social adjustment (Chronister, Chan, Sasson-Gelman, & Chiu, 2010). These negative consequences associated with caregiving could be lessened with social supports, available resources, and appropriate coping skills.

Having knowledge of family structure and how TBI affects families can help rehabilitation counselors successfully work with families with TBI. I believe that The Circumplex Model of Family Systems is a great tool for counselors to understand families undergoing the stressors related to TBI. Understanding the coping responses within the family

structure suggests that knowledge of post-TBI family structure might be helpful for rehabilitation counselors in addressing the specific needs of families of TBI (Curtiss, Klemz, & Vanderploeg, 2000).

Counselors working with families of individuals with TBI can help plan family assessments, interventions, and help in the development of long-term family support systems by knowing the families type (Kosciulek & Lustig, 1999). Counselors can assist families cope using positive appraisal, where the family redefines their stressful event to make it become more manageable. Another coping technique may be managing the family tension by taking a break from the care of the family member with the TBI and opening expressing their feelings and frustrations (Kosciulek, 1994). By using appropriate coping skills, the family may have a better chance to have a positive long-term outcome and have better family functioning.

A major challenge for rehabilitation counselors is determining what elements of intervention are the most appropriate as well as effective with which presenting problems and with which elements of family functioning (Kosciulek, 1996). The Circumplex Model provides a guide for determining the family's needs. Understanding that family caregivers are crucial partners in the plan of care for their family member with a TBI can significantly help rehabilitation professionals plan and assess services for the individual as well as for the family. For the future of rehabilitation counselors working with families with TBI it is essential to see that there is a need for service systems to be individualized and flexible to respond to the changing family needs (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). Some families may need many services later on and some families may need supports in the early stages of recovery. Family caregivers also need more ongoing information and education regarding TBI, financial assistance available, and respite care. When giving information to families regarding TBI and

services available, rehabilitation counselors should regularly check to see if the family understands their family member's condition, care, and their future needs (Paterson, Kieloch, & Gmiterek, 2001). Having a clear understanding of what they know and what they need will help both the family and the rehabilitation team.

Rehabilitation counselors should develop a process of give-and-take in which they provide leadership toward family goals and invite the family to teach them about the complexity of their situation.” (Midori Hanna, 2012). To assess family functioning the rehabilitation counselor must understand the nature of the problem(s) the family is facing including their cause, possible solutions and the counselors role in the process of providing assistance. The family should understand that the counselor is working for them and with them. Denial and resistance may be encountered among families that are struggling with outcome of TBI. In response, the counselor use a strength based approach, drawing attention to new and positive developments, pointing out how far the family and the individual with TBI have traveled, and affirming new sources of strength.

Rehabilitation counselors should be involved in the recovery process as soon as it is possible. In the early stages of rehabilitation, the family is included in discussions of the client's goals, expected duration of rehabilitation and therapeutic plan, risks, and any barriers to discharge. Throughout the early stages of inpatient rehabilitation, the family is asked to articulate the goals that the rehabilitation plan will be developed to meet, such as ‘returning to work’, ‘playing sports again’, and the like. The families have the central role in setting these goals since knowledge of the client's pre-injury status and personality are important for creating a plan that is personally relevant. Goal-setting activities are repeated with the family as the client makes progress. The client is included in goal setting as well, once able to participate in the

conversation. The counselor's goal is not just to help family members cope in adverse conditions but also to improve outcomes for the family member with TBI.

Much can be accomplished through the involvement of family members in counseling rather than just working individually with the identified client will continue. Before counselors can effectively employ family counseling, they will need a grounding in family counseling theory. The Circumplex Model, which is a systems model of family counseling, can provide important information and guidelines for counselors who work with families. Using this model involves an assessment of family cohesion and family adaptation to the TBI.

Using the Circumplex Model as a guide, rehabilitation counseling tasks and goals should first focus on reducing problems or symptoms that pose an immediate threat to family balance. For families who lack education about TBI this would involve the provision of information. For caregivers struggling with work, transportation and other barriers, the counselor can be useful in referring that family to the appropriate services to resolve these issues. According to Olson (2000), goals related to the family system include working with the family toward balance, perhaps in the redistribution of tasks around the home or involvement of the individual with TBI in activities that would create some space for other family members to spend time attending to their own needs. Involving all members of the family in rehabilitation plan development is one task that may help develop family cohesion. Most important is any work that can be done to improve communication between family members. The overarching preventative goal is to move the family toward greater flexibility, and increase in their ability to navigate changes in the future. Supporting the families attempts to be proactive advocates for the injured family member is very important to support the family's self-efficacy. It may be necessary for the rehabilitation counselor to connect the family with a more formal marital and family therapy process. This

should be considered given the counselors ethical obligation to work within their scope of expertise. Developing interdisciplinary connections in addition to connections with resources in the community would be an important practice for rehabilitation counselors.

Given the important role of family in the recovery of individuals with TBI, rehabilitation counseling training programs should consider a greater emphasis on family systems education as part of the rehabilitation-counseling curriculum. Not all families experience a long-term problem but require assistance in the moment. If the problem is secondary to a disability, this is an area where rehabilitation counselors are expert. As the literature review indicated, barriers and obstacles are frequently based on lack of information and environmental barriers. Rehabilitation counselors who are familiar with the dynamics of family systems therapy can help the family using the practical application of advocacy and community integrations skills to allow the family to negotiate these barriers. At the same time, the counselor can aid the individual with TBI toward an improved psychosocial outcome.

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Research Paper Title:  
The Effects of Traumatic Brain Injury on Families

Major Professor: Jane L. Nichols