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Family Coping and Adaptation to Traumatic Brain Injury

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The abstract and thesis of Richard Francis Burton for the Master of Science in Education: Counselor Education were presented May 15, 1996 and accepted by the thesis committee and the department.

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ABSTRACT

An abstract of the thesis of Richard Francis Burton for the Master of Science in Education: Counselor Education presented May 15, 1996.

Title: Family Coping and Adaptation to Traumatic Brain Injury

The purpose of this thesis is to (a) briefly describe the dynamics of traumatic brain injury (TBI) that most commonly affects the family including: injury characteristics, personality changes, psychosocial implications, and the family impact; (b) research and summarize the literature that pertains to the impact of TBI behavior; (c) review and explain considerations for families and counselors working with the injured patient and each other; (d) review published empirical studies on specific support interventions that address family adaptation and coping methods for those that are facing TBI; and (e) review compare and contrast relevant TBI materials designed to measure effective coping strategies, as well as future considerations for researchers studying the family and TBI.

In the United States, traumatic brain injuries have taken the lives of more people than have died in all of Americas wars and takes the lives of more people under the age of 34

than all other causes combined. Head traumas that result in a TBI survivor produce long-term deficits in the injured member that dramatically reduces their ability to function within the broad ranges of normalcy.

Families are considered the integral variable in the rehabilitation of their injured member and must often cope with the caregiving as well as the grieving process simultaneously.

Traditional counseling techniques are insufficient in establishing the support these families need therefore, intervention strategies are recommended for families with TBI members. The ever increasing numbers of people sustaining a TBI indicates a need for interventions and techniques that allow for families to the loss and shock with empowerment and knowledge. There remains a need for the creation of a simple, easy to read, instrument that educates families and gives options based on their individual needs. Even with the needs of the family slowly becoming more recognized in the areas of TBI, proactive coping strategies remain slow in development.

FAMILY COPING AND ADAPTATION
TO TRAUMATIC BRAIN INJURY

By

RICHARD FRANCIS BURTON

A thesis submitted in partial fulfillment of the
requirements for the degree of

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in
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This thesis is dedicated in memory of my mother, June A. Ochs and my brother, Dean R. Burton and all who loved them.

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INTRODUCTION

> Fibers as delicate as those of which the organ of mind is composed are liable to break as a result of violence to the head.
>
> [JHP Gamma, 1835]

Scope of the Problem

The family has long been considered an integral variable in the rehabilitation of an injured member's adaptation and adjustment to a disability. Head traumas that result in a traumatic brain injury (TBI) induce long term deficits to the injured member that dramatically influence and change their interpersonal, emotional, and vocational functioning. In a majority of the cases, a person functioning at least within the broad ranges of normalcy, suddenly becomes emotionally and intellectually dysfunctional (Ross, Ben-Yishay, Piasetsky, Rattock, Lakin, & Diller, 1983). Research studies indicate that the number of individuals with significant brain damage each year vary from 350,000 (Rosenthal, 1987) to 8.8 million people (Shordone, 1987), and every 15 seconds, someone in the United States suffers a traumatic brain injury. Bush (1988) further elaborates on the problem of TBI when he writes:

> The United States has a brain injury problem of massive proportions. In the United States more

> persons have died of brain injury than have died in all of America's wars. Brain injury takes more lives of people under the age of 44 than any other single cause, and it takes more lives of people under the age of 34 than all other causes combined. It is the number one public health problem, with approximately 1,500,000 injuries, 500,000 hospital visits, 60,000 to 70,000 moderate to severe cases, and 2,000 persons left in a persistent vegetative state each year. The annual cost is determined to be many billions of dollars and the cost in terms of human anguish is astronomical. (p. 74)

Since the long term effects of a traumatic brain injury (TBI) tend to be overshadowed by the immediacy of medical and rehabilitative treatment, family support and information on how to cope and adapt to this family disruption and life changing event remains scant and much needed (Bergland & Thomas 1991; Brooks, 1984; Brooks & McKinlay, 1983; Groveman & Brown, 1985; Henry, Knippa, & Golden, 1985; Johnson & Higgins, 1987; Kosciulek, 1994; Reeber, 1992; Rogers & Kruetzer, 1984). What is known through extended research, is that family life is suddenly altered and the injured individual often develops a distinctly different personality often far removed from the previous self. Since families are bound by filial and fraternal ties that extend beyond rehabilitation support, the roles of primary caregivers often become their responsibility following release to the community.

While many families will often see the positive in their injured member's survival, they remain besieged with issues of denial, loss, and grief in the diminished cognitive and physical abilities that once buoyed that member's character and independence. A number of physicians and rehabilitation professionals have hypothesized that the adaptation to the traumatic brain injury is at least as great for the family and its members, as for the injured individual (Brooks, 1984; Kosciulek, 1994; Reeber, 1992; Rogers & Kruetzer, 1984), and in most cases, the mental consequences of injury outweigh the physical ones placing a greater burden on the injured member's relatives (Bond, 1979).

Traditional counseling is insufficient in creating and establishing the support these families need to function successfully. Often the problem receives little attention until it has reached an unbearable magnitude. A study in 1983 by the New York Medical Center described a portion of their findings:

> Families come into treatment programs such as ours, usually after long periods of stress. They are generally exhausted. The trauma of the initial accident, the lengthy illness and erratic course of recovery (during which period brain injured patients become extremely regressed or violently acting-out), the difficulties of reintegrating the brain injured person into the family structure, the fears of an unknown future for the patient all coupled with feelings of inadequacy, guilt, and helplessness, contribute to the picture of a family living under a great deal of stress. Even a family that was a smoothly functioning unit may begin to fall apart under the burdens of such difficulties. (Ross et al., 1983, p. 114)

Ongoing professional support and adaptive techniques are necessary in the development of a proactive, problem solving program designed to alleviate the considerable strain on the TBI family. This remains of paramount importance since the more families are able to cope and adapt, the greater influence they will have on the patient's recovery and social reintegration (Bergland & Thomas, 1991; Brooks, 1984; Kay & Cavallo, 1994; Kosciulek, McCubbin, & McCubbin, 1993; Mauss-Clum & Ryan, 1981; Rogers & Kruetzers, 1984).

The purpose of this thesis is to: (a) briefly describe the dynamics of TBI that most commonly affects the family including: injury characteristics, personality changes, psychosocial implications, and the family impact; (b) research and summarize the literature that pertains to the impact of TBI behavior; (c) review and explain considerations for families and counselors working with the injured patient and each other; (d) review published empirical studies on specific support interventions that address family adaptation and coping methods for those that are facing TBI; and (e) review, compare and contrast relevant TBI materials designed to measure effective coping strategies, as well as future considerations for researchers studying the family and TBI.

Dynamics of TBI

Injury and Characteristics

Sustained traumatic brain injury is estimated to cost the United States $500 billion dollars per year, or 12 percent of the Gross National Product (GNP) (Durgin, Rath, & Dales, 1991) and estimates for lifelong treatment per individual with TBI can exceed $4.5 million (Nobel, Conley, Laski, & Nobel, 1990).

It encompass a broad population that is usually made up of adolescent and young adults under the ages of 35; additionaly, men are twice as likely as women to suffer head trauma (Vanost-Wultz, 1993). Traumatic brain injuries have been classified into two types:

1. <u>Closed head injury:</u> The most common of the two, that involves no penetration of the cranial vault. Its cause is often a rapid acceleration/deceleration, whereby the brain is whipped back and forth in a quick motion. This motion most frequently results from automobile accidents. An additional type of injury can result from a blow to the head with the primary damage occurring at the time of assault, or later with secondary characteristics resulting in edema (swelling of the brain) or the formation of hematomas (a swelling filled with extravasated blood).
2. <u>Open head injury:</u> This injury results in damage to the skull through penetration (e.g., gunshot), and the resulting damage may include bone fragment lacerations, severed blood vessels, brain matter destruction, and invasion of the meninges (the three membranes containing the brain and spinal cord). The prognosis for recovery from a penetrating injury to the head depends on the location of the injury, the extent of damage, and the type of lesion. The likelihood of seizures is much higher with a penetrating injury than one in which the skull was uninjured (Falvo, 1991; Vanost-Wultz, 1993).

Traumatic brain injury may also occur when there is a loss of oxygen to the brain (anoxia) due to the results of cardiac arrest, stroke, suffocation, drowning, and cerebral palsy. The brain injury typology can vary greatly in the specific symptomatology depending on several factors that include extent and location of the injury, length of coma, and age of onset.

Personality Changes

A major cause of stress on the family following TBI is the individual changes the injured member goes through, experienced both physically and psychologically. The physical effects ranging from sensory-motor disturbance to post-traumatic epilepsy are well known and are often a lifelong sequelae to the injury. The behavioral and emotional responses that alter the individual's personality are often associated with the high subjective burden placed on their family (Brooks & McKinlay, 1983).

Distinct and dramatic personality changes have been attributed to traumatic brain injuries and recorded as far back as the 1800's. Harlow (1868) describes a 19th century railroad worker, Phinaeous Gage, who drove a tamping bar through his frontal brain lobe and survived. Despite making a complete physical recovery, he was described as having marked personality alterations described as apathy, childish immaturity, lability, and loss of appropriate social behavior. O'Shannick and O'Shannick (1994) state that a TBI injury, regardless of its severity, will cause a "diffuse axonal injury" that alters one's ability to slow or stop inappropriate behaviors:

> Diffuse axonal injury results in the "unplugging" of neural networks from one another with a decrease or loss of the associational matrix within the central nervous system (CNS). These changes create "networking" lapses for the individual during functional activities. Lapses may vary from transient problems with initiation that affects one's ability to appropriately begin a pattern, such as a conversation or a problem - solving sequence, to more overt problems with stopping ongoing behaviors. (p.165)

Personality changes are often a direct result of problems associated with post-injury recovery and rehabilitation. A study by McKinlay, Brooks, Bond, Martinage, and Marshall (1981) listed the ten most frequently reported problems cited by relatives and caregivers as being present in a TBI survivor as the following: slowness, tiredness, irritability, poor memory, impatience, tension, anxiety, bad temper, personality change, and headaches. A clear trend toward personality disorders and the ten most frequently reported problems by relatives remained consistent over a twelve month period of study.

Thomsen (1984) described similar results in a 10-15 year follow-up study on the late outcome of severe blunt head traumas. In her research, Thomsen describes the most common problems as being: poor memory, poor concentration, slowness, loss of concentration, spontaneity, tiredness, sensitivity distress, lack of interests, and specific changes in personality and emotion. The personality and emotional changes were categorized as childishness, emotionality, irritability, restlessness, and disturbed behavior. Lezak (1978) explained alterations in personality and their relation to frontal lobe injuries as: impaired social perception, impaired self-control and regulation, stimulus bound behavior, emotional change, and inability to learn from social experience. These behavioral dysfunctions in conjunction with the inability to retain prior-to-injury personality, creates a strong potential for family avoidance and alienation. The lack of personal insight and distinct changes that proceed unheeded, along with the diminished forms of interpersonal awareness represent an organically-based agnosia (failure to recognize one's behavior) that has been labeled as "organic denial" (O'Shanick & O'Shanick, 1994).

The alterations in personality that can be attributed to TBI, confuse family members unprepared for the massive changes in character. The changing characteristics either increase or decrease as time goes by, rarely remaining consistent. These fluctuations and varying patterns of personality receive descriptions such as "frontal lobe syndrome" but the titles are oversimplified and not conducive to providing adequate descriptions of what is occurring in the neural/emotional linkage (Prigatano, 1986).

Understanding the common traits that are often associated with TBI (e.g., poor memory, irritability, poor anger management, and immaturity) help families understand the sudden personality changes that are likely to occur. Thomsen (1984) reports lack of insight and understanding on the part of the TBI client, in response to his/her personality changes, as making resolutions to family problems and the adaptation process difficult. Brooks and McKinlay (1983) have suggested that personality change alone is not the entire cause of subjective burden, and that other factors including personal resources and specific qualities of the relative are important factors in the genesis of total burden.

Prigatano (1986) lists a schema for classifying personality disorders that is helpful for family members and clinicians to address when working and living with the TBI patient. While there is clearly no definitive list of the reactionary, neuropsychologically-based, or characterological problems, the following problems (see TABLE 1, page 10) are frequently seen in clinical settings as being typical for these broad categories.

The list assists in having the problem behaviors addressed in some form of cognitive retraining and in assisting in social development beyond rehabilitation and home environments. Teaching the family and its members to recognize the distinct changes as well as skills to assist in the management of personality disorders remains a crucial component in the adaptation process.

TABLE I
Schema for Typical Personality Disorders after Brain Injury

Reactionary Problems

Anxiety
Depression
Irritability
Mistrust of others
Hopelessness
Helplessness (i.e., more demanding attitude)
Anger
Social withdrawal
Phobias

Neuropsychologically Mediated Problems

Impulsiveness
Socially inappropriate comments or actions
Emotional lability
Agitation
Paranoia
Unawareness of deficit (or severity)
Childlike behavior (giddiness or insensitivity to others)
Misperception of the intentions or actions of others
Apparent lack of motivation
Hypoarousal

Characterological Styles

Obsessive or super orderly behavior
Hardworking attitude
Congeniality or friendliness
Social deceptiveness (psychopathic tendencies)
Desire to maintain satisfying interpersonal relationships
Encouragement or discouragement of family support
Distrustfulness
Feeling not getting "enough" help from others and therapists
Avoidance of insight into self or discussion of personal topics
Enjoyment of upsetting others
Enjoyment of dependent role
Defiant attitude (challenging therapist to go ahead and treat them if they can)

Adapted from Prigatano,
(1986, p. 396).

Psychosocial Implications

Traumatically brain injured patients face additional repercussions following injury that extend beyond personality and physical alterations. Many are confused and feel out of step with the world around them despite reassurances. Symptoms of TBI and cognitive impairment create additional problems of reintegration and acceptance that often stymie the effectiveness of ongoing rehabilitative treatments. Psychosocial consequences of TBI are difficult to treat because of a lack of useful and concrete knowledge (Livneh & Antonak, 1994). Psychosocial prognosis is important for the planning of rehabilitation as well as for making other practical decisions after traumatic brain injury (Vilkki, Ahola, Ohman, Servo, & Heiskanen, 1994), and psychosocial reintegration is considered to be the ultimate goal of rehabilitation (Kaplan, 1991), yet studies on the psychosocial outcome fail to communicate the impact of the brain injury on people's lives (Lezak, 1978).

There are now exceptions to this as evidenced by the volumes of material listing psychosocial adjustment, impairment, and reactions to TBI (See Antonak, Livneh & Antonak, 1993; Bergland & Thomas, 1991; Livneh & Antonak, 1994; Prigatano, 1986, Rosenthal, 1987). Common psychosocial problems after brain injury include an inability to maintain gainful employment, loss of pre-traumatic friendships, impaired sense of body image, reduced self-esteem, and enhanced dependency on family and welfare systems (Prigatano, 1986).

Rosenthal (1984) describes disorders of communication in the brain as:

> ....usually less severe than the results of other acquired neurological disorders (e.g., stroke, tumor). Nonetheless, disorders such as aphasia, dysarythia, apraxia can impair the patients ability to cope and communicate. Impaired communication skills can adversely affect a persons ability to function independently in activities of daily living or in vocational pursuits and thus create a greater burden for significant others. (p. 229)

Impaired communication and other limitations imposed by TBI are often immediate and may progress as time goes by. This relationship between loss of effective communication and psychosocial implications involved with TBI individuals is highlighted by Marshall (1989):

> The ability to communicate in detail distinguishes man from all other organisms. Impairment, temporary or permanent, of this ability has profound effects in the psychological, social, and vocational spheres of life. To be unable to process language efficiently or lack sufficient speech motor control to articulate one's thoughts is to have one of life's most confusing, bewildering, and devastating problems. (p. 87)

According to Bond (1975), overemphasis on the physical recovery in the study of head injured patients is often recognized as the major area of concern in rehabilitation. He discovered a significant relationship between psychosocial impairment and a strong disruption of family cohesiveness brought on by the injured member's inability to effectively deal with their psychosocial and personality impairments.

Bond (1975) discovered a strong deterrent to family involvement was related to the TBI member's level of disability, the more severe the perceived disability, the less the family wished to be involved with that member.

Family involvement is an integral part of the recovery process, because the family often assumes the responsibility for physical care as well as management of psychosocial problems associated with the head injury (Bergland & Thomas, 1991).

Bergland and Thomas (1991) expanded on the tremendous changes that are caused by severe head injury that can alter the individual's personal constructs and role status within the community. This status of sudden disablement is particularly difficult because few culturally positive images deal with disability or head injury, and families tend to bring their own prejudices to the situation. Livneh and Antonak (1994) further state that:

> The inability to accomplish, for no apparent reason, what were previously facile tasks in everyday life leads to profound self-doubt, worry, and anxiety when confronting new situations. Although denial may have psychological utility, with specific behaviors motivated by a need to keep cognitive, perceptual, and motor deficits out of awareness, it is thought to have an organic basis manifest a failure or inability to self-monitor. (p. 32)

An additional stress on the family is the long-term psychosocial complications of brain injured patients. One area of psychosocial difficulty is failure to return to work. The limiting factor in the ability to sustain employment following TBI is not the severity of damage per se, but the accompanying self-doubt and personality problems (Klonoff & Prigatano, 1987). Assistance is needed to address the problem of post-rehabilitation psychosocial implications and the importance it plays in the successful reintegration following TBI. Prigatano (1986) also has found a correlation between the ability to return to work and improved psychosocial well being. Writing on how to work with TBI clients, Prigatano advised:

> Personality disturbances after brain injury have been shown to influence psychosocial adjustment greatly. Work and interpersonal relationships cannot be adequately maintained unless these affective problems are modified. Methods of personality assessment and therapeutic intervention are greatly needed for the rehabilitation of brain injured adults and children. (p. 50)

Impact on the Family Structure

The impact of TBI on the family alters the entire structure which inevitably leads to a disrupted balance and change in roles. Ongoing difficulties that many families may encounter include: (a) emotional, personality, and behavioral changes in the member with the injury; (b) lack of information and appropriate services; (c) financial burden; and (d) emotional strain because of prolonged caretaking (Kosciulek, 1994). The struggle of the family to "right itself" and reestablish a new homeostasis after TBI in one member is parallel to the process of rehabilitation and adjustment in the injured person (Kay & Cavallo, 1994).

In many cases following TBI, relatives are forced to become primary caregivers and are given little insight on the lifelong burdens they will face. Livingston and Brooks (1988) suggest that the burden on caregivers after head injury is easier to appreciate than to define and that "...it involves the multiplicity of social, emotional, and physical impacts the injury has on caregivers. It also depends greatly on the perception of the caregiver and his or her capacity to cope" (p. 8). Brooks (1984) reflected two different (although related) ways in which a family might be burdened:

1. Objective burden type 1 - changes in family routine, family health, housing conditions, financial status, and social and leisure activities.
2. Objective burden type 2 - post-traumatic symptoms and changes to the patient's behavior.

Subjective burden is stress felt by the persons caring for the patient, resulting from the presence of objective burden. Brooks (1984) further explains that "...there is the subjective burden or the stress actually felt by family members caring for the patient." (p. 129) Livingston, Brooks and Bond (1985) contend that "perhaps it might be helpful to see these care-giving relatives as potential full-time, non-professional therapists." (p. 874)

The burden of prolonged dependence in conjunction with the personality and psychosocial consequences following TBI, make it a unique family problem not shared by other types of life changing disabilities. Rosenthal (1984) recognized the distinct difference when he wrote:

> .... unlike other severely disabled adults (e.g., spinal cord injury), the brain injured adult usually displays a variety of cognitive and behavioral deficits that adversely affect the patients ability to function effectively within the community and family system. Such deficits are often of indefinite duration and can result in prolonged dependence on family members. This state of dependence is often linked to the inability of the head injured adult to achieve an adequate measure of social and vocational rehabilitation. (p. 227)

Livingston and Brooks (1988) also note the differences prone to head injured families when they maintain:

> Head injury families face a variety of social difficulties that are often related to personality changes in the head injured patient and that can lead to family friction. Deterioration in the social functioning of the relatives is slower to evolve than mood disturbance. A chain of events occurs in the dysfunctioning family after head injury: poor patient outcome in the psychosocial sphere is associated with the persistence of dysthymic states in the relatives, which in turn may lead to major role shifts in the household. (p. 12)

A comparison study of the wives of paraplegic men with the wives of severely brain injured by Rosenbaum and Najenson (1976) derived several conclusions, most notably:

1. Wives of brain injured men perceive greater change in family life than wives of paraplegic men.

2. Wives of brain injured men evaluate life changes as more disabling than the wives of paraplegic men.

3. Wives of brain injured men show more evidence of depressed mood than the wives of paraplegic men.

The wives described their head injured partners as more self-oriented, childish, demanding, and dependent. The head injured men took a smaller role in the household responsibilities including care of the children. A reported increase in depression, significant loss in social lives, and a reduction in affection and sexual activity was consistent in their findings.

Lezak (1978) described a "social limbo" that head injured spouses live in, increased role changes, and the stress of being unable to divorce their partner with dignity or a clear conscience.

Brooks (1984) concluded from his research study that:

1. Wives of brain injured patients report drastic life changes.
2. Life changes are associated with depressed mood.
3. Interpersonal relationships within the family become tense following brain injury.
4. Wives of brain injured patients become lonely and isolated.
5. Wives of the brain injured had to assume husband's role.

Neurobehavioral symptoms and the distress placed on family members have been well documented since the 1970's. The documentation by researchers indicates congruent results in recognizing the traits and specific definitions of burden placed on family members and primary caregivers. Kay and Cavallo (1994) describe that depression in family members correlated not primarily with the severity of injury, but with the number and extent of cognitive symptoms, as well as with failure to return to work and with social isolation.

Bergland and Thomas (1991), in a study to further clarify social burden and perceived isolation following TBI, obtained similar findings. They found that in 92 percent of their respondents who had suffered a TBI, friends were supportive while the individual was hospitalized, but relationships tapered off once deficits became apparent. The same percentage of respondents recognized changed friendships with friends, not openly rejecting the TBI patient, but rather avoiding and ignoring them. Prigatano (1986) reported that family members cannot fully comprehend the personality disturbances following TBI and purposely avoid the relative or assume that he or she "isn't trying". Prigatano further maintains that:

> Personality changes after trauma result in a significant loss of pre-accident friendships. While family members can often tolerate a brain-injured young adult who can not be gainfully employed, they have an extremely difficult time handling the breakdown of interpersonal relationships. (p. 49)

The increased dependency on other family members and public systems of support, create depression among family members and may force long-term separation or eventual divorce (Burton & Volpe, 1993; Brooks, 1984; Prigatano, 1986). Livingston and Brooks (1988) believe that depression may be triggered by current life stressors, such as lack of a confidant or partner, the presence of three or more school-age children in the home, and being of lower socioeconomic status. From these variables, those who face major stress without support are more vulnerable to breakdown. Role shifts placed upon the wives and family members force additional responsibility and disruption of family dynamics, increasing family burden and confusion. Some families can function well as a unit but still experience and face difficulty when coping with a family member's TBI. Families feeling disordered, alienated, and overwhelmed are likely to collapse as a result of a family member becoming severely disabled (Reeber, 1992). Bishop and Miller (1988) reviewed the literature and family assessment techniques for coping with a members TBI. From their data, they deduced that:

1. The families experience stress.
2. The severity of brain damage, behavioral and social change, and caregiver personality traits all relate to the level of distress experienced by families.
3. TBI patients underreport difficulties compared to their relatives.
4. The highest perceived difficulty is emotional change.
5. Symptoms and difficulties are consistent over time.
6. Cognitive and dependency problems are related to the duration of post-traumatic amnesia (PTA) while emotional and behavioral changes are also related but to a lesser degree.

7. The longer the period of post-traumatic amnesia (PTA) the greater the burden on the relatives.
8. Social support does not offset the burden for families.
9. A perception of help available does buffer the burden.
10. There are families who cope well despite severe TBI.

The true extent of family burden remains difficult to measure and strategies to combat the ongoing loneliness, trauma, and powerful destructive effects of TBI remain in perpetual motion. Understanding the dynamics of TBI and learning to initiate a proactive treatment plan, targeted at pinpointing maladaptive behaviors in the patient as well as the family, are essential tools in prevention and assistance to both groups of survivors.

CHAPTER II

Intervention Strategies with TBI Survivors

Intervention following a traumatic brain injury constitutes one of the most important steps in both patient and family recovery. Intervention, when implemented early in the rehabilitation process, creates an environment directed at proactive coping skills for the family and caregivers, as well as providing a necessary climate for the patient to return to a state of independence. A close working alliance between family, patient, rehabilitation professionals, and the community, help in the creation of definitive goals for those looking for ongoing contacts in this phase of family rehabilitation.

Interventions should be both educative and supportive since without relief, the family and primary caregivers eventually become angry, resentful, tired and frustrated. Strategies for interventions should strengthen the family bond as well as the coping skills in hopes of the family and caregivers not reaching a point of wishing to give up care of the patient.

The Resiliency Model

The resiliency model is linked in origin to the stress and coping work of Reuben Hill (1958) and the typology Model of Family Adjustment and Adaptation of McCubbin and McCubbin (1991). The model is designed to protect the family from breakdown and to facilitate adjustment to head injury. Family adaptation is a process in which families engage in direct response to the excessive demands, depleted resources, and the realization that systematic changes are needed to restore stability and satisfaction in the event of a head injury (Kosciulek, McCubbin & McCubbin, 1993; McCubbin & McCubbin, 1991). The resiliency model is comprised of two major phases, adjustment and adaptation.

<u>The Adjustment Phase.</u> The adjustment phase is characterized by a series of interacting components that shape the family processes and outcomes. Families attempt to maintain patterns of interacting roles, and rules that have been established to guide day to day family activity (Kosciulek, McCubbin & McCubbin, 1993). McCubbin and McCubbin (1991) stressed that outcomes of family adjustment efforts can vary along a continuum of positive outcome (bonadjustment) to negative outcome (maladjustment).

Bonadjustment is characterized by a continued maintenance of family functioning and control over TBI influence, while maladjustment is characterized by a deterioration of the family ability to fulfill and accomplish life tasks. Kosciulek et al. (1993) maintain that:

> The most common consequences of head injury for the family are often negative. Existing family capabilities are inadequate to meet the emotional, social, and financial demands placed on the family

> as a result of having a member with a head injury. Families are not likely to achieve stability without making substantial changes in family roles, priorities, goals, and rules. In these situations involving the disruption of established family patterns, the family will in all likelihood experience maladjustment and a resulting state of crisis. (p. 41)

The Adaptation Phase. Family adaptation is the central concept in understanding the focus of a family's struggle to manage a member with a head injury over time. It has been used to describe the outcome of family efforts to bring a new level of balance, harmony, coherence, and a satisfactory level of functioning to a family following head injury (Kosciulek, McCubbin & McCubbin, 1993; McCubbin & McCubbin, 1991). The level of family adaptation is determined by the coping responses and interactions following an immediate pile up of demands created by the crisis situation. The resiliency model adaptation phase shown in Figure 1 (see page 24) illustrates adjustment along a continuum directly reflecting family efforts to overcome the demands of TBI and the family interactions.

Kosciulek et al. (1993) describe the positive levels of bonadaptation as: (a) positive physical and mental health of individual family members; (b) continued facilitation and promotion of individual members development; (c) optimal role functioning of individual members; (d) maintenance of a family unit that can accomplish its life cycle tasks; and (e) maintenance of family integrity and sense of control over

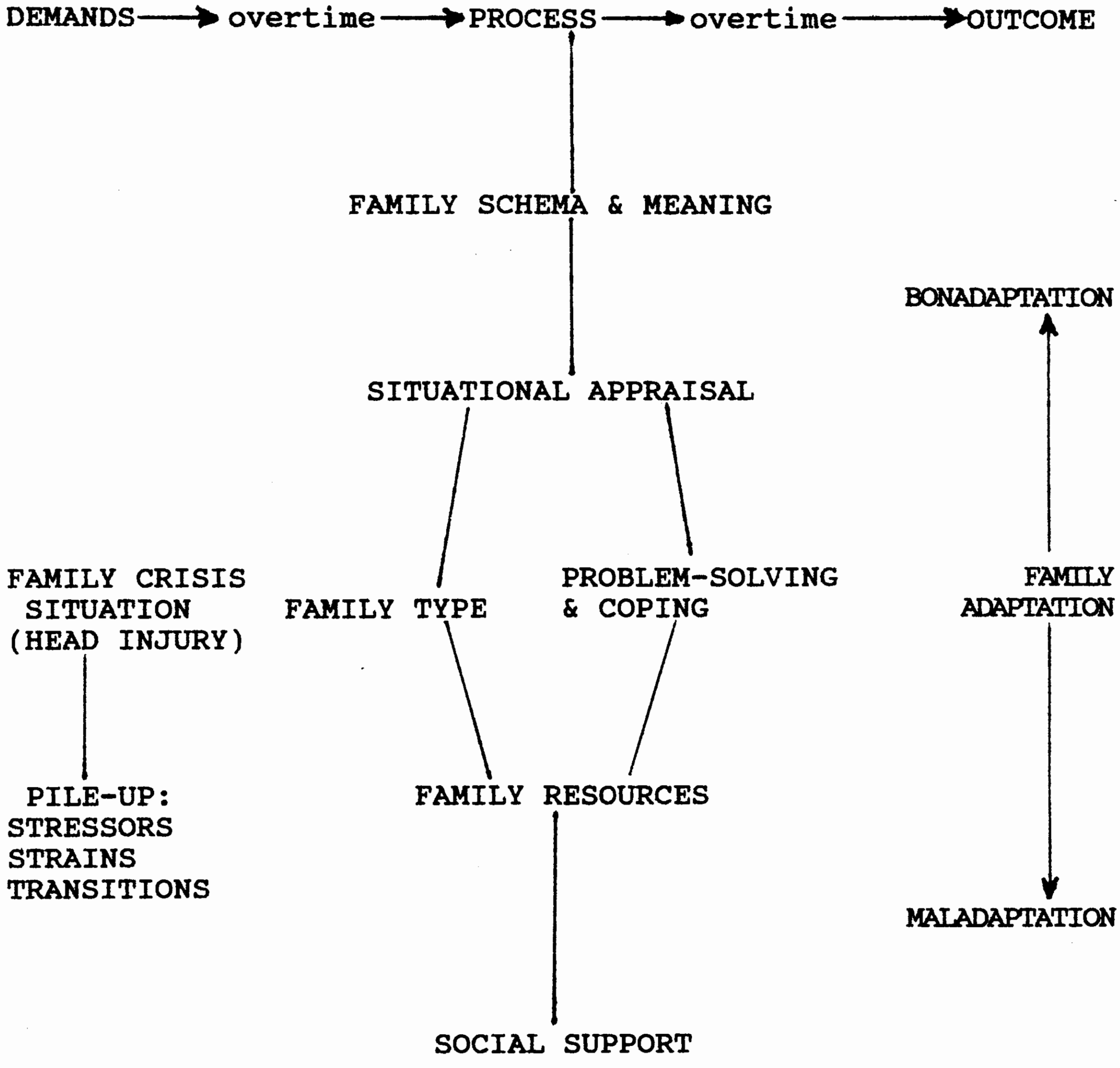

FIGURE 1.1
Adaptation phase of the resiliency model of family stress, adjustment, and adaptation.
[Adapted from Kosciulek, McCubbin & McCubbin, 1993, p. 42]

environmental influence. Family maladaptation at the negative end of the continuum is characterized by a continued imbalance at one of two family functioning levels: (a) individual to family; or (b) family to community.

Patterson (1988) proposes an important distinction between family adaptation and adjustment, in that adaptation usually evolves over a longer period of time and has long-term consequences, and adjustment evolves over a shorter time period and has short-term consequences. Kosciulek et al. (1993) state that family adaptation is a process in which families engage in direct response to excessive demands, depleted resources, and the realization that systematic changes are needed to restore stability. They further conclude:

> Family adaptation is not confined strictly to internal changes. It is not sufficient for families to merely restructure internally. They must also maintain a level of rapport and interaction within the community at large. A quality social support system and long-term community support services (e.g., respite, support groups) are critical ingredients for positive family adaptation to head injury. By isolating characteristics of individual members, the family system and the community that shape family behavior over time, the Resiliency Model of Family Stress, Adjustment and Adaptation describes the process of family adaptation to head injury. (pp. 44-45)

Kubler-Ross' Strategic Therapy Model

Traumatically brain injured individuals are often compared to terminally ill patients, and the family's acceptance of the injury often parallels the core issues of loss, dependency, stress, guilt, denial, and the need for adaptation proposed by Kubler-Ross' (1969). A closed head injury, like cancer, is a continuous reminder to family members of their own mortality and vulnerability (Groveman & Brown, 1985).

Kubler-Ross (1969) describes denial as the most frequent reaction to the realities of an illness. Similarly to the terminally ill, denial is often the first emotional reaction of TBI. In fact, families may collude with the patient and use denial as a vehicle for avoiding their own feelings of inadequacy, anger, or helplessness (Groveman & Brown, 1985).

The initial shock of TBI leaves family members immobile as ambiguous explanations associated with post-trauma impair decision making skills and cause additional worry and apprehension. Henry et al. (1985) describe the denial stage following TBI:

> Denial may be expressed in many ways, though two types of denial are most common. In the first, the family does not fully recognize the brain injured person's deficits. The family may find refuge in the belief that the injured person will fully recover. They do not consider the significance of professional advice that the patient may be permanently paralyzed or speech impaired, or unable to return to a former occupation. The family may push the injured person to pursue former activities and interests, at the expense of appropriate treatment and remediation. In the second form of denial, families may show evidence that they are not emotionally capable of accepting the brain injured persons disabilities. If pressed to examine those disabilities, they may become severely withdrawn, depressed, punitive, or divisive with each other, or otherwise express serious lack of ability to manage their daily

> activities and stresses (e.g., child care, employment, self-care). (p. 434)

In the process of counseling the family through the denial stage, therapy might initially consist of reviews of the patient's strengths. Groveman and Brown (1985) discovered that when therapy consisted of focusing on one polarity (strengths), family members would eventually focus on the opposite polarity (deficits), easing the strength and duration of the denial stage. They further propose that "... as a general rule of thumb, a family therapy discussion of strengths facilitates the loosening of a patient's and family's rigid position of denial" (p. 442).

Anger is considered the second stage of Kubler-Ross' model and the astute therapist remains cognizant of the fact that anger frequently signals that the walls of denial are cracking (Groveman & Brown, 1985). Communication with the family may break down following frustration that the patient does not resume the former role within the family system (Henry et al., 1985). Both separate and family counseling sessions are beneficial to progress and to restructuring the ability to understand and comprehend the emotional signals of anger. Uncovering the source of the patient's and family's frustration can have a dramatic affect upon curtailing anger and refocusing emotional energy into more productive channels (Groveman & Brown, 1985).

The third stage of the Kubler-Ross' model is defined as bargaining; this incorporates a self-imposed deadline on acceptance. In TBI patients, bargaining frequently revolves around the patient's desire for treatment termination and is viewed as a form of magical thinking. Therapists and rehabilitation professionals are viewed as a dispenser of normalcy, so if the therapist determines that therapy must be terminated, it will signal the patient's readiness to resume activities performed prior to the TBI. The therapist or rehabilitation professional can use this stage to better elicit advice and work through this portion of the Kubler-Ross' model. Groveman and Brown (1985) describe the goal of neutrality:

> During the bargaining stage it is critical for the therapist to remain neutral. This helps the therapist while affording the patient and other family members an opportunity to explore their feelings and examine alternative solutions. Additionally,it underscores for the family that they can be in control, and are responsible for important aspects of their lives. (p. 444)

The depression that exists in stage four of the model may not be amenable to a confrontive psychotherapy approach since the patient and family are mourning their "loss" and are not succumbing to irrationalities (Groveman & Brown, 1985). Attempts to dissuade feeling of depression may hinder the acceptance of the family member's condition and increase denial and anger. Families are encouraged to express loss and sorrow. This is the time for the therapist to wait and listen to the family without demanding suggestions.

Groveman and Brown (1985) state that stage five, the acceptance stage, is a time in which the primary question becomes "where do we go from here?" and families no longer make unreasonable demands on the patient or act in an overprotective fashion. By using the Kubler-Ross' model and its approach at framing the core issues of loss and eventual acceptance, Henry et al. (1985) offer the following "strategic therapy" as an alternative approach to family therapy:

1. The therapist's principle task is to determine how the family system has responded to the brain impaired individual (recall, if the therapist is not aware from the initial referral that a brain injury exists, the therapist is challenged to recognize and follow through on subtle cues of brain injury). The therapist must determine the family's definition of the problem, and the attempts they have made at solution.
2. The therapist's next major task is to determine reasonable goals for therapy. This might require the "reframing" of the problem in a manner commonly acceptable to family members and conducive to change. Caution must be exercised because frequently, the specific symptoms of brain injury (which may be minor and have little significance), while being the immediate identified source of stress, may actually only highlight the family's inability to cope with preexisting unresolved conflicts, dissatisfactions, or simple daily problems.
3. Once the problems have been defined, a therapeutic contract is formulated that outlines the initial goals and

length of the therapeutic involvement. This contract can be renegotiated as "new" problems are defined or if additional time is necessary for the accomplishment of the original therapeutic goals.

4. Once the contract has been negotiated the therapist must track the interactional patterns and important themes (e.g., husbands should always be the "breadwinner") which help to create and/or maintain the "problems" within the current family system. Based on this information, interventions can be designed that simultaneously provide additional feedback about the system and the opportunity for change. These interventions should be consistent with the family's "language" and living contexts.

5. The therapist consults with a neuropsychologist or suggests that a neuropsychological evaluation be completed. As stated previously, precise understanding of the nature of the brain impairment and its cognitive and behavioral manifestations is critical for therapy. Furthermore, the therapist should be willing to request that the neuropsychologist use clear, easy to understand, concrete terms to describe the brain injured persons limitations. The therapist must be conversant enough with TBI to educate the family, respond to family members questions, and to recognize denial and confront it when appropriate.

6. The therapist must understand the other professional groups (e.g., physicians) impinging on the family and

ascertain how these systems will relate to the family therapy. Strategic interventions might be necessary to circumvent resistance or to "reframe" the family in relation to these other professional systems.

Rape et al. (1992) caution against a strong adherence to the assumption that all families go through the stages of intense depression or denial. They further warn against the term "normal" when referring to how families adapt to TBI, and that this type of labeling may be counterproductive. Wortman and Silver (1989) argue against the implied assumption that families have to go through a stage of mourning in coping with loss and further maintain that such assumptions have not been empirically tested. They further maintain that:

> Recognition of ... variability is crucial in order that those who experience loss are treated non-judgementally and with the respect, sensitivity, and compassion they deserve. (p. 355)

Family Network Intervention

To answer the varied needs of families facing TBI, one of the most useful of the clinical strategies is the family network intervention. Having been recognized as one of the most promising models (see Rogers & Kruetzer, 1984), a documented approach of systematically organizing and strengthening a family support system has evolved. The procedure involves the gathering of immediate family members along with the extended family, friends, acquaintances, and community ties for several group problem solving sessions.

Mauss-Clum and Ryan (1981) concluded that families identify their relatives and friends as being their greatest source of emotional support, and that the network intervention utilizes the filial and fraternal bonds to direct this strength towards assistance and ongoing support.

Bergland and Thomas (1991) concluded that lack of support from family, friends, school, and work fostered poor social functioning in the TBI client as well as loss of autonomy and continued dependence. Moreover, participation of family, friends, community support, and rehabilitation professionals serves as the foundation for ongoing participation and patient cooperation (Bergland & Thomas, 1991; Hegeman, 1986; Kay & Cavallo, 1994; Rogers & Kruetzer, 1984).

The network concept is one of autonomous function that does not require the aid of facilitators and many of the families are less likely to become isolated and overburdened if others are made aware of the ongoing struggles of coping with TBI. By utilizing a large resource pool of support members, the family minimizes the potential of exhausting themselves and having additional burdens. Some of the solutions that Rogers and Kruetzer (1984) recommend are:

> 1) The network may find part-time employees or supervised recreation for the head injured patient twice a week; 2) A group may plan an outing with the head injured person; 3) The network implements limit setting or behavior modification system to relieve tension involved with caregiving; 4) The school system provides individualized instruction or organized activities; and 5) The local head injury foundation chapter provides social interaction at least once per month. (p. 345)

The process of setting up a network intervention is usually initiated through hospital staff or rehabilitation professionals who have ongoing contact with the family. The concept is discussed with the family members who are asked to list potential participants who will agree to help and attend a family contact meeting. During the initial meeting, the primary focus is on structuring the network by building on strengths of pre-existing relationships. Nursing and mental health professionals educate the family and friends regarding the effects of the injury and probable outcomes.

After goals are formulated and established, each participant is given a role or task that signifies his or her responsibility. Implications may include scheduling meetings with large numbers of network members, overcoming the denial of the injury effects and limitations, and coping with crisis situations that may alter the network schedule. Despite the implications, networks function effectively in sharing the burden of increased responsibility following TBI. Rogers and Kruetzer (1984) advise discussing issues openly within the network to develop practical management strategies that readjust expectations, address the needs of individual members, and deter crisis by providing families with appropriate information and support skills. With ongoing assessment and the use of family members and friends, family network intervention has proven to be an effective addition in facilitating coping and adaptation as well as in relieving the daily stressors that accompany TBI.

Family Education Intervention

Medical and rehabilitation professionals can help families cope with a traumatic brain injury through the use of information and education. Families need to know the physiological and psychological results of TBI and what can be expected from the injured member both immediately and in the future. It is unrealistic to expect families who are suddenly thrust into untried and bewildering roles to fulfill their new role expectations unaided (Reeber, 1992). A sudden dependency on strangers who care for the patient, sudden financial strains, family problems, and a general loss of stability can keep a family from fully understanding the needs of the patient. Klonoff and Prigatano (1987) advise the use of the educative model as the most basic intervention:

> It has been our experience that the educative model, including presenting research findings and relevant patient data, provides explanations of why patients behave the way they do. The more the relatives understand the effects of brain injury, the more adequately they can cope with the patients behavior. By reducing their confusion, ultimately, their degree of distress may be lessened. (p. 397)

According to Ross et al. (1983), rehabilitation specialists should be aware of how important family education, involvement, and support are to the rehabilitation of the family member who has suffered. Their study further maintained that the process of "education" bears a strong resemblance to didactic (i.e., teaching) sessions, in which: (a) the therapist explains to members of the family the nature of the many behavioral observations, and the patients feelings (sometimes with the aid of various "posters"); (b) the therapist "models" in front of the family the ways in which the patient can and should be communicated with and "handled" in general; (c) the therapist outlines procedures and at times issues "directives" about the ways in which the patient's behavior at home should be managed, in order for it to become stabilized (pp. 116-117).

Family education interventions are designed to provide information about the TBI, and its long-term consequences, and to help families develop a greater understanding of the disability. During the education sessions, a family is presented with the materials (e.g., books, handouts, publications from journals) to better help them understand the implications of head injury and what changes are likely to encounter. Highly structured education plans that teach families to adapt and cope while prioritizing the information on an individual basis, is strongly recommended (Reeber, 1992).

A better adjusted, better educated family facilitates a positive outcome for the patient by anticipating problems and developing a realistic plan (Johnson & Higgins, 1987). Johnson and Higgins (1987) assert that the educational intervention and use of family dynamics should include the following components for a stable system: (a) primary contact and resource person; (b) family support group; (c) orientation to the head injury unit; (d) formal exchange of information about rehabilitation goals; (e) shared educational objectives; (f) scheduled teaching sessions; (g) nursing care plan developed with family input; (h) shared discharge planning; and (i) standardized documentation of each component. Once informed, using the education model, the reintegration of the injured person becomes a process of applying what has been learned, adjusting it to the needs of the particular family, and incorporating it into the family environment (Rosenthal & Young, 1988). Despite strong recommendations for the use of The Family Education Intervention, no studies were found that provided quantifiable evidence of the benefits of family education (Reeber, 1992). Unsuccessful attempts using the Family Assessment Device (FAD) in measuring educational intervention with successful family functioning prompted Reeber (1992) to state "... the FAD and the family education series were not correlated for this study and developing an instrument measuring family education objectives may be appropriate" (p. 336). The timing of providing information is crucial in the early stages of recovery, families need to sustain hope and cannot be overwhelmed with dire warnings and pessimistic predictions (Kay & Cavallo, 1994). Educational intervention is essential in the development of a therapeutic alliance between support professionals and family members. If staff has been unable to make adequate contact with the family, typically less is achieved in terms of educating and supporting both the patient and his or her family (Klonoff & Prigatano, 1987).

Despite reports that Family Education Intervention has generated only little data in support of its use (Reeber, 1992), an overwhelming number of clinicians and specialists see it as necessary for ongoing adaptation and family success following TBI. (Johnson & Higgins, 1987; Klonoff & Prigatano, 1987; Rosenthal, 1984; Ross et al., 1983)

Family Support Groups

Family support groups create a unique dimension in coping and adaptation to TBI by facilitating a group discussion and problem solving session shared by others facing similar implications. Many families desperate to have questions answered or to share experiences that effect their lives, acknowledge group supports as a continuation of the education model with peer support. During the sessions, a wide variety of topics are discussed, including the nature of brain injury, the rehabilitation process, psychosocial deficits, mobility skills, perceptual-motor deficits, and community resources. (Rosenthal, 1984)

Support groups provide increased family involvement in the gathering of information from others who have faced similar problems, as well as encouraging active involvement with head injury advocacy, legislation, prevention, and ongoing community education. Support groups have been shown to correct misconceptions about rehabilitation of head injury, as experienced members discuss problems and progress of the rehabilitation process (Johnson & Higgins, 1987). Because the material is presented in a structured educational format, families react positively to the program and feel comfortable and at ease in sharing their own frustrations and experiences (Rosenthal, 1984). Participation in support groups is steadily becoming a method used in decreasing the uncertainty of outcome following a relative's injury. Watson (1987) emphasizes the redirection of focus away from morbid thoughts and unproductive activities into productive activities, specifically support groups. The attendance at support sessions for families of TBI patients gives family members direction during a chaotic time and provides them with encouragement and feelings of accomplishment. Bergland and Thomas (1991) maintain the importance of family participation as a reformation of family structures and individual goals:

> Individual and family involvement in problem definition and resolution of personal family, relationship, school, and vocational issues can be an act of empowerment and control. Moreover, such participation can serve as a foundation for cooperation and communication between community members, rehabilitation professionals, and injured individuals. (p. 20)

One of the first "grass roots" organizations to address the unmet needs of TBI family members was founded by a parent and called "The High Hopes Recovery Group" in Southern California. Initial tasks were centered around programs designed to retrain cognitive, vocational, and social skills while parents were involved in a support group. Since organization success provided a model for others sharing interest, the National Head Injury Foundation was developed in Massachusetts with varied services that include:

1. A resource and clearinghouse for gathering and dissemination of head injury information.
2. Provision of emotional support for families.
3. Group development information and support throughout the United States.
4. Development of parent support groups and "hot line" counseling services.

Rosenthal (1984) describes support groups as providing necessary peer support, exchanges of information, practical problem solving, and mutual assistance in coping with unsettling burdens of TBI. Support groups run by consumers provide an important alternative source of counseling and support that may be more effective than services provided by health care professionals (Mauss-Clum & Ryan, 1981; Rosenthal, 1984).

Regular meetings and sincere emotional connections to those facing similar circumstances decrease the feelings of isolation and helplessness associated with TBI. The environment of family support groups clearly indicate a trend that focuses on less threatening environments and greater understanding of individual attitudes and aptitudes. Group support and unity in dealing with the maladaptive patterns associated with TBI is one form of intervention that seems likely to continue in both popularity and growth.

Considerations for Families and Counselors

The preceding chapters were written on the basis of generalizations about families. The importance of recognizing that all families are different and require individual assessments, is crucial. It is important that the individual support staff not project their personal value systems and beliefs in lieu of family needs and levels of adjustment. The purpose of this information is to assist both families and professionals in establishing a balance and style that works best for those wishing to utilize coping and adaptation methods suited for the level of need.

Brooks (1984) suggests that it is never easy to predict which families will be most burdened by the presence of an injured patient. Livingston, Brooks, and Bond (1985) found that families with men who have suffered a severe head injury, experience more psychiatric disturbances then families of men who have had a minor head injury. Their study demonstrated a need for support and coping skills based on the level of individual needs. Johnson and Higgins (1987) recognized the unpredictability in planning interventions for families with TBI when they wrote:

> Even in its grief and uncertainty, the family will make attempts to help the patient and assure

> his or her future. These efforts can be independent and disorganized. They can also run directly counter to the efforts of the staff, resulting in the need for conflict resolution. Or, with a well developed plan, the family's effort can coincide with those of the staff, allowing all concerned to direct their attention and energy to the head injured patient. (p. 332)

Klonoff and Prigatano (1987) state that family reactions are very heterogenous, and for successful reintegration to take place in the home, community, and if possible, work, a strong working alliance with the family members is imperative. They further maintain that:

> It has been our experience that developing a therapeutic alliance with the patients family can be a slow process. It can take several months, and the rehabilitation staff needs to persevere and obtain support from co-workers in how best to work with the family. If staff has been unable to make adequate contact with the family, typically less is achieved in terms of educating and supporting both the patient and his or her family. With a true therapeutic alliance, relatives commonly report that they feel the rehabilitation staff has done as much or more to help them as they have done to help the patient. (p. 401)

Counselors should consider the fears and apprehension families express following TBI as normal and recognize the stressful predicament these families now face. Many feel they are on their own with little hope of ever living a "normal life" despite professional reassurances of the many possibilities that exist with medical technology. McCubbin and Figley (1983) listed seven primary crisis like TBI. These seven stressful areas include:

1. Little or no time to prepare.
2. No sense of anticipation.

3. No previous experience.
4. Few sources of guidance.
5. Little sense of control.
6. A great sense of loss.
7. Feelings of anger associated with emotional and medical problems.

The importance of community reintegration and ongoing support is essential in alleviating the considerable strain previously described, yet many believe this is the optimal time for implementing a plan of intervention with the families. Kay and Cavallo (1994) emphasized the importance of intervention after rehabilitation is complete when they determined:

> Family interventions usually become more needed, more intense, and longer term. The crucial turning point occurs when, after all formal rehabilitation ends, the family as a system faces the challenge of being able to reconstitute as an effective and functional system with a new balance and identity. Not all families are able to do so. In families who cannot, the life cycle is seriously disrupted, and individual members may be blocked from making natural life transitions in a healthy way. (pp. 560-561)

Even with intervention strategies put in place families and therapists must work for the best service plan given the needs of the family. Kay and Cavallo (1994) warn against therapists misinterpreting family needs with the infusion of their own values and perspectives when they report:

> ....clinicians must be careful to sort out what is detrimental in the eyes of different family members. The decision to intervene when the self-sacrifice is in the service of homeostasis raises

> difficult countertransference and ethical issues, which must be dealt with honestly both within the therapist and directly with the family. Often it is when a family member reaches a developmental transition that the family becomes destabilized, and productive intervention can begin. (p. 561)

Families making the transition to acceptance and effective integration of coping and adaptation often face momentary set-backs. These setbacks are often attributed to specific rights of passage that the injured member may not be able to accomplish. These transition points and life-cycle disruptions result in episodes of loss and open old wounds once thought to be healed. Kay and Cavallo (1994) highlight this situation as well as solutions faced by many families when they state:

> ....a family may adapt quite well to a severe head injury in a young child, but when his or her peers begin Little League and he does not, when dating, high school graduation, college, and marriage do not occur as they naturally would, there is sadness for the family and a retouching of old hurts and losses. It is crucial during this period to help families build on their own strength and dignity, and especially important to enable the person with the brain injury to find a productive and meaningful place in the family, with peers, and in the community. (p. 561)

Counselors and family members are strongly advised against predicting the eventual outcome of the injured person and planning for specific changes that may never occur. It is of obvious importance to many families following a TBI that their needs are as important as those of the injured member. For without their strength and stability, successful rehabilitation is unlikely to occur. Since it is the goal of all therapists to help meet the needs of their clients, creating a communicative alliance with families and those helping to serve them establishes an atmosphere that will respect the family and its individuality.

CHAPTER III

FAMILY COPING AND ADAPTATION TO TBI: A REVIEW OF THE RESEARCH LITERATURE

Reviews and research concerning the phases of family coping and adaptation to TBI remain ongoing and much needed. Various authors have focused on the longitudinal study of TBI and its devastating effects on the family. The increased efficiency of the health care system and the effectiveness of neurosurgical techniques have improved the likelihood that individuals who sustain a severe brain injury will survive (Willer, Allen, Liss & Zicht, 1991). It has been this increase in medical technology and the lifelong sequelae following TBI that continues to increase the need for additional research into the study of brain injury and the ways in which it affects the family. The controversy surrounding family coping and adaptation to TBI is in the injury generalizations made by physicians and rehabilitation professionals in diagnosing and correctly informing the family of the injured member's condition and potential deficits. While it remains difficult for these professionals to pinpoint what the injured member will have difficulty with, many health care providers simply cannot provide the answers family members need (Mauss-Clum & Ryan, 1987; Rosenthal, 1984).

Brooks (1984) contends that difficulties in communication between clinicians caring for the injured person, and the person's relatives arise from the family member being unable to understand clinical explanations. This lack of understanding is often coupled with the inability of the family member to dispute the information received. Brooks (1984) discovered in his review of head injury organizations in England and in the United States, that over 50 percent of the family members interviewed felt that information and support services for coping were inadequate. One can clearly recognize a relationship between lack of information for coping and adaptation, and the lengthy denial many families go through following injury. This denial and the inability to understand the patient's changing behavior has been linked to emotional changes in family members, and eventual marital breakdown (Brooks, 1984; Thomsen, 1981).

It is the purpose of this chapter to offer a readable cross-sectional review of literature that could be used as assistance for families in the process of coping. In each section, a brief description is provided of the study sample involved, methods of measurement, and the specific findings. In addition, tables are provided when necessary to support information on the interventions used.

Coping among Mothers and Siblings of Young Adult Males with TBI

Young adult males under the age of 35 comprise the highest proportion of individuals suffering TBI, and there are twice as many men as women who suffer head traumas (Vanost-Wultz, 1993). Brooks (1984) mentions that young adult males dominate as subjects in TBI research and are often the center of the samples in family coping studies. Willer et al. (1991) recognized this when they assessed "...men with TBI typically outnumber women with TBI two to one, it is not surprising that the focus has been on men" (p. 460).

Despite the clear overdominance of males in TBI research studies, little has been written on the problems and coping of individual family members, their roles, and their style. Willer et al. (1990) discovered that there is little known about the perception of the affected individuals themselves, their parents, and siblings. Using a similar hypothesis created by Karpman, Wolfe, and Vargo (1985) in which they interviewed adults with TBI and their parents in exploring the process of TBI adjustments, Willer and colleagues looked to define the problems and coping methods from three separate groups.

The three groups consisted of young adult males between the ages of 14 and 25 at least 18 months postinjury and living with parents. The remaining two groups were comprised of mothers and siblings who were asked to participate in the study as part of the research proposal. Announcements about the weekend study retreat were distributed through the Ontario Head Injury Association (OHIA) and all chapter affiliates. Twelve families participated in the retreat. The average age of the young men with TBI was 20 yrs. (ranging from 14 to 25 yrs.). The average age of the mothers was 47 (ranging from 39 to 59 yrs.). A total of seven brothers and sisters (siblings) attended with an average age of 17 yrs. Willer et al. (1990) used a highly structured nominal group technique that involves posing a question to the group, allowing time for individuals to write a list of answers, and having group members contribute one idea at a time until all the ideas have been shared. Ideas were prioritized by anonymous written ballot, and a final list judged most important was produced. The three seperate groups involved in the study included: (a) young adult males with TBI; (b) mothers of young adult males with TBI; and (c) siblings of young adult males with TBI. All three groups were posed the question of identifying family problems related to TBI then discusssing strategies that helped them cope.

1. Problems identified by young adult males with TBI. The young men in the group described frustration with others who focused on their deficits and did not recognize their strengths as the most significant problem (see Table 2, pages 49-50). They indicated that family members were overprotective and would not allow them to take minor risks to

Table 2
Problems and Coping Strategies Identified by Mothers, Siblings, and Young Males with TBI

Problems identified by young adult males with TBI	Problems identified by mothers of sons with TBI
1. Abilities are not always recognized by others	1. Difficulty accessing appropriate services
2. Difficulties in experiences in gaining new friends and retaining old friends	2. Behavior problems and mood swings of sons
3. Difficulty is encountered in controlling behavior	3. Impact of son's injury on siblings
4. Family stress	4. Disruption of family life
5. Problems in school	5. Legal problems
6. Physical limitations and accessibility problems	
Coping strategies identified by young adult males with TBI	Coping strategies identified by mothers of sons with TBI
1. Developing and maintaining a good outlook	1. Developing a healthy outlook
2. Support from family and friends	2. Accepting son as he is and not dwelling on how he used to be
3. Taking an active role in rehabilitation	3. Communicating with son
4. Taking an active role in the community	4. Encouraging son to participate in social activities
5. Educating the public	5. Educating the public

Table 2
Problems and Coping Strategies Identified by Mothers, Siblings, and Young Adult Males with TBI
(continued)

Problems identified by siblings of brothers with TBI	Coping identified by siblings of brothers with TBI
1. Family distress	1. Supressing feelings and frustrations
2. Concern for the future of their brothers	2. Becoming educated about TBI
3. Change in family lifestyle	3. Becoming assertive with others
4. Barriers to autonomy for their brother	4. Making time available for sibling
5. Increase in personal responsibilities	5. Communicating within the family

Adapted from Willer et al. (1990, pp. 169-171).

improve abilities and the public's misconception of them. Difficulty in making friends and relationships with peers being seen as problematic ranked second. Many felt that they had nothing to offer the opposite sex and felt uncomfortable around them. Problems with speech, anger, impatience, impulsivity, and an inability to control their behaviors ranked as the third most significant problem. Causing family stress and arguments about their behavior and ongoing legal matters ranked fourth. Problems in school and multiple failures in many subjects was ranked fifth.

2. Coping strategies identified by young adult males with TBI. The young men in the study agreed on five specific coping strategies and believed that developing and maintaining a good outlook was number one on their list. The young men described clear goals that are sensible and attainable as being helpful. Second on the list but listed as most essential in overcoming the limitations imposed by their disability, was the support of their family and friends.

Ranked at number three, was taking an active role in their rehabilitation and believing that it was the only way progress could be obtained. The need for the freedom to take risks and to reintegrate back into the community was listed as the fourth most significant coping strategy. Educating the public about head injury was listed as the fifth most significant coping strategy with an emphasis about the consequences of driving under the influence of alcohol.

3. Problems identified by mothers of sons with TBI. Mothers of the group provided a litany of problems related to the access of services needed for their sons. Because the study was conducted in Canada, where health services are funded by a government operated health insurance plan that places severe limitations on the access to services for individuals with disabilities, this was listed as the most significant problem. Highlighted in this group of accessing appropriate services was the school system and appropriate programs for people with TBI. Behavioral and mood problems were listed as the second most significant problem with all mothers in agreement that this is the most troublesome consequence of TBI. The impact of TBI and its effects on the siblings in the family ranked third with many of the mothers describing the siblings as taking on additional responsibilities for their disabled brother. The fourth most significant problem reported by mothers was the disruption of family life and the stress experienced by family members as a result of the TBI.

Many of the mothers described their marriages not surviving the strain and stressors of caring for their injured sons and ending in divorce. Legal problems and the complications of ongoing litigation was listed at number five. This included the ongoing court battles to ensure financial support for their injured son's future.

4. Coping strategies identified by mothers of sons with TBI. The mothers first coping strategy was the same as that of their sons, namely, developing a healthy outlook. The group leaders observed that the mothers were extremely devoted to their sons and that this devotion had not diminished even after many years. The second most significant coping strategy listed by mothers was accepting their son as he is and to not dwell on the past and how he used to be. This included developing a realistic appraisal of his capabilities and abandoning previous hopes and aspirations. Mothers in the group felt that open communication with their sons was important to maintain and this was listed as the third most important coping strategy. The open communication allowed mothers in the group to encourage their sons to participate in social activities and to simply become involved outside the home. It was listed fourth. Educating the public, including public school educators, was listed as the fifth coping strategy. Many mothers felt that their (self-described) aggressive methods were often necessary to emphasize their point and simply being heard had a significant coping effect.

5. Problems identified by siblings of brothers with TBI. Family distress and steady tension were listed as the biggest problem, yet all the siblings described their own contributions to the problem over their impatience and the limitations of their brothers. Listed as second, the siblings noted an overwhelming concern for the future of their brother

and what would happen to them when their parents were no longer able to care for them as well as the future quality of life that lies in store for the brothers as adults. A change in family lifestyle was listed as number three with an emphasis on a fierce loyalty to their injured brother and defending them against strangers and classmates. Barriers to autonomy was problem number four. Many of the siblings felt that their parents were overprotective and did not allow their injured sibling enough freedom. An increase in personal responsibilities was designated as the fifth most significant problem listed by the siblings. Many assumed care for their injured brothers and felt that they had become "assistant parents".

6. Coping strategies identified by siblings of brothers with TBI. Interestingly, the number one coping strategy by siblings of brothers with TBI exactly matched that of able-bodied husbands coping with their TBI wives in a similar study developed by Willer and colleagues in 1991. Suppressing feelings and frustrations was listed as the most significant coping strategy. The behaviors that accompany TBI (i.e., immaturity, impulsivity, apathy, agitation) caused many of the siblings to suppress feelings and "develop patience". Becoming educated on TBI was listed second since many of the siblings were extremely well informed and described the continued use of periodicals, texts, workshops, and questioning professionals as helpful. Becoming assertive with

others concerning their brothers and encouraging people to view their brothers as individuals and not the disability was listed as number three. Making time available for the brother and being a friend as well as a relative was listed as number four. Lastly, siblings felt that communication within the family and open, honest discussions of expectations for their injured brother should be listed as the fifth most significant coping strategy. The siblings suggested that an objective person, such as a family counselor could be helpful in such discussions, but none of their families have received such assistance.

Willer et al. (1990) cited their research as useful to families but felt researchers could learn from their results when they observed:

> The value of this discussion component to our research is immeasurable. It provided us with a perspective and understanding that is not usually present in survey research. Because all questions were completed prior to the discussion, we believe that we have developed a successful combination of survey and observation research. Finally, we recommend this method of investigation because it is not only edifying, but enjoyable for the participants. In a rare occurrence in psychological research, our subjects thanked us for the opportunity to participate. (p. 172)

Coping Among Spouses of Persons with TBI

Much of the TBI research that focuses on the family has centered on adolescents and young males who have sustained a head injury through risky behaviors. In fact, there is some evidence that head injured persons do not comprise a random sample of the general population. Brooks (1984) mentions in his research an overabundance of males with unsatisfactory backgrounds prior to injury. Often times, it is these males that comprise much of the samples in TBI studies with other groups often being misrepresented in the research.

One such group that has been rarely studied, has been individuals with TBI, their spouses, and the ways in which both groups cope with severe head injury (Willer et al., 1991). In addition, few studies have been completed that focused primarily on married couples. Of those studies (Brooks & McKinlay, 1983; Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Rosenbaum & Najenson, 1976; Thomsen, 1981), a very bleak outcome emerged. Methods of dealing with the sudden onset of TBI remained as bad or worse when compared in follow-up studies with couples one to seven years after injury (Oddy, Coughlan, Tyerman, & Jenkins, 1985).

Willer et al. (1991) recognized that most research on behavioral and psychosocial sequelae of TBI has depended on interviews with family members or professional staff; little efforts have been focused on the specific concerns of individuals with TBI. They sought a sample of married couples to participate in a retreat. The 31 families were found through an advertisement placed in the Ontario Head Injury Association and consisted of 20 participants with an injured husband and 11 with an injured wife. All were married or lived together in a marriage like relationship.

A specially designed nominal group technique was used which involves posing a question to the group, allowing time for individuals to write a list of answers, and having group members contribute one idea at a time until all the ideas have been shared. Ideas were prioritized by anonymous written ballot, and a final list of ideas judged most important was produced, the exact same method used by Willer et al. (1990). There were four separate groups that included: (a) wives with TBI; (b) able bodied husbands; (c) husbands with TBI; and (d) able bodied wives. Each group was asked to respond to the following two questions: "What problems have you and your family faced since the head injury?" and "What have you and your family done that has helped you cope with these problems?". Answers were categorized as follows:

1. Problems of TBI spouses. Not surprisingly, problems and coping strategies identified by persons with TBI were similar in many respects (see Table 3, page 58). Wives and husbands both listed a general loss of independence and autonomy as their most important problem concerning a TBI. The second ranked problem for wives was loneliness and depression, while the men patients second most significant problem was a loss as their role as "bread winner". Women with TBI listed a diminished interest in sex due to chronic headaches and backaches, men with TBI felt that living with their limitations was the most frustrating in rank number three, pain and limitations as fourth. Both groups with TBI

Table 3
Problems and Coping Strategies Identified by Spouses with TBI

Problems identified by wives with TBI	Problems identified by husbands with TBI
1. Loss of autonomy	1. Loss of independence
2. Loneliness	2. Loss of role of husband, father, provider
3. Diminished interest in sex	3. Difficulties associated with recognizing and adapting to their limitations
4. Pain and limitations in activities	4. Loss of memory
5. Personality changes	5. Personality change
6. Reduction in memory/cognitive abilities.	

Coping strategies identified by wives with TBI	Coping strategies identified by husbands with TBI
1. Spouse and family support	1. Being included in family decisions
2. Support groups	2. Understanding the concerns of other family members
3. Memory aids	3. Involvement activities outside the home
4. Becoming assertive and assuming family responsibility	4. Development of a realistic apprasisalof their limitations
5. Rehabilitation programs	5. Use of organizational and memory aids
6. Spirtual belief	

Adapted from Willer et al. (1991, p. 462).

listed personality changes and mood swings as the fifth most common problem. This correlates strongly with a study completed by Oddy et al. (1985) in which patients listed mood swings and often losing their temper as the fifth most common problem in a similar seven year follow-up study.

2. Coping strategies of TBI spouses. Willer et al. (1991) found that coping strategies in their study differed dramatically between men and women with TBI. Women listed spouse and familial support as the most important coping strategy, especially support from their husbands. Surprisingly men with TBI reported that simply being allowed to be included in the family decisions was the most important strategy. Women listed the importance of support groups as the second most important coping strategy following TBI. This remains consistent with the opinion of other researchers (Johnson & Higgins, 1987; Mauss-Clum & Ryan, 1981; Rosenthal, 1984; Watson, 1987) as an important factor in patient coping with TBI. The men with TBI felt that trying to understand the concerns of family members should be included with being allowed to participate in family decisions.

For women, the use of memory aids ranked third in coping strategies; this ranked fifth for men. Men found that getting involved with activities outside the home, especially volunteer work in local community service programs was important enough to be ranked third. Spiritual belief was listed by women only in the group, and it was listed last.

3. Problems identified by able-bodied spouses. Willer et al. (1991) discovered problems and coping strategies to be vastly different when comparisons were based on gender (see Table 4, page 62). The problems that were most significant for the able-bodied wives whose husbands suffered TBI, were personality changes and the cognitive difficulties that their head injured spouses exhibited. Able-bodied husbands listed their wives loss of autonomy and severe mood swings as the number one and two most common problems in that order. Wives felt that a lack of insight and acceptance of their disabilities ranked third followed by a signifigantly reduced income resulting from job loss. The able-bodied husbands third ranked problem was a general insecurity and overprotectiveness. Fourth on the husbands list was the injured wife's reluctance to leave the home. A general change in lifestyle rounded out the husbands list in the fifth spot. Wives of TBI males listed a loss of emotional support and companionship they had received from their husbands ranked fifth in order. Wives listed the sixth most important problem to be their husband's TBI affecting the growth and development of their children.

4. Coping strategies by able-bodied spouses. Willer et al. (1991) found coping strategies of able-bodied spouses to be vastly different from each other. The two most effective coping strategies women described were: (1) identifying problems in a realistic but optimistic manner and (2) becoming

assertive in dealing with the daily obstacles they encountered. Able-bodied husbands believed that suppressing one's feelings when reacting to the mood swings and personality changes and not attributing all the family's problems to the head injury as the two most effective coping strategies. Able-bodied wives believed that allowing their TBI husbands to increase their independence ranked third. Getting away from family pressures and taking time for oneself ranked fourth, followed by participation in support groups rounded out the wives coping strategies. Able-bodied husbands described the use of support groups as fourth in importance, but only for their TBI wives to participate in, not themselves. Finally, the fifth ranking cited by the husbands was the use of humor for appraising problems to make them seem less severe.

Willer et al. (1991) observed that participants in the study with TBI, both men and women, listed loss of autonomy as their biggest concern and problem they faced. Also worth noting, was the differences between the genders regarding the importance of memory and communication. Gender differences had little impact on problems of spouses with TBI who constantly placed disabilities in the context of the limitations they imposed on role performance (Willer et al., 1991). Gender differences, however, were evident in how TBI spouses choose to cope with their injury. The differences related strongly to social sex-role expectations.

Table 4
Problems and Coping Strategies Identified by Able-Bodied Spouses

Problems identified by able-bodied husbands	Problems identified by able-bodied wives
1. Wife's loss of autonomy	1. Changes in husband's personality
2. Wife's mood swings	2. Changes in husband's cognitive abilities, including memory loss
3. Wife's insecurities and overprotectiveness.	3. Husbands lack of insight and acceptance of his disabilities
4. Wife's reluctance to leave the home	4. Reduction in financial resources
5. General change in lifestyle	5. Loss of emotional support, sharing and companionship
	6. Feeling unable to meet children's needs
Coping strategies identified by able-bodied husbands	**Coping strategies identified by able-bodied wives**
1. Suppressing one's feelings	1. Developing a realistic but optomistic outlook
2. Being careful not to attribute all family problems to the head injury	2. Becoming assertive with disabled husband, health care providers, in-laws and insurance representatives
3. Mutually definig new roles and responsibilities	3. Allowing husband to be independent
4. Support groups for the wives	4. Taking time for one's self and going on family outings
5. Maintaing a sense of humor	5. Participation in support groups

Adapted from Willer et al. (1991, p. 463).

Able-bodied spouses in the study listed problems with personality change and mood swings as the most problematic, this discovery confirms Brooks and McKinlay (1983) in which spouses and relatives of TBI patients perceived personality change as very evident. The relative's toleration of this personality change drops over time, leading to an increase in burden. The use of support groups was surprising given the ongoing research in favor of their use for all able-bodied relatives and spouses coping with TBI. In their study, Willer et al. (1991) write:

> One further example of how men and women differed in their coping strategies was their use of support groups. The women with TBI and the able-bodied wives of men with TBI described support groups as very helpful. The able-bodied husbands perceived such groups as helpful only for their wives. The men, particularly the able-bodied husbands, described coping strategies that were highly individualistic, such as suppressing feelings. The men were also more likely to engage in problem focused coping strategies, stressing reformulation of problems, than in coping strategies that involved emotion. (p. 64)

All participants warned against the belief that TBI recovery can be predictable, and strongly argued against neuropsychological and psychosocial assessment guides that predict outcomes for brain injured individuals. Many of the participants pointed to the perpetually changing ways in which both groups, able-bodied and those with TBI, must expand their coping efforts. Livingston, Brooks, and Bond (1985) discovered similar findings in their three month follow-up study with relatives following a severe head injury when they write:

> The overriding impression despite early difficulties in marital and close family relationships is relatives continuing to function ably in a number of different social roles. (p. 874)

Despite the issues of such a small sample and the manner with which the study was conducted, there remained a high level of similarities between this study, and those that may be considered more valid and reliable. The study revealed coping strategies (e.g., suppressing one's feelings, defining new roles and responsibilities, maintaining a sense of humor, understanding the needs of other family members) and useful insight previously not thought to exist between TBI patients and their family members.

Family Coping Dimensions

Families and their abilities to cope with the implications of TBI vary along a continuum. While some families are strong, decisive, and organized, posing a lower threat for collapse, many families are labeled high risk due to their pre-accident dysfunction. Evidence of alcoholism, marital problems, anti-social behavior, and general insecurities in the family prior to TBI are apt to be overwhelmed by the burdens of coping and adjustment (Rosenthal, 1984). Family coping and adaptation is sometimes initiated by health care professionals who first map the characteristics of the family in general - the ages, roles, economic status, resources, education, willingness to commit, and support systems (Hegman, 1986). Bergland and Thomas (1991) observed the need for added insight by professionals working with TBI families when they write:

> Professionals need to address the tremendous changes caused by severe head injury that can alter the individual's personal constructs and role and status in the family and the community. The status of the sudden disablement is particularly difficult, because culturally few positive images deal with disability or head injury, and furthermore, individuals and their families bring their own prejudices regarding disability to the situation. (p.17)

Kosciulek (1994a) described in his study the huge toll head injury costs the family both emotionally and interpersonally. This emotional and interpersonal strain stems from ongoing difficulties that the families encounter and include: (a) emotional, personality, and behavioral changes in the injured member; (b) lack of information and appropriate services; (c) financial burden; and (d) emotional strain because of prolonged caretaking. Kosciulek (1994a) collected data from 150 families drawn from the family support groups of the Wisconsin Brain Trauma Association (WTBA). The sample required that the family member who was the primary caregiver complete the questionnaire, and that the family member with the head injury was at least one year post injury and 18 years of age.

Kosciulek (1994a) developed an instrument called the Frequency of Family Coping Behaviors (FCB) Rating Form. Participants were asked to rate each of the 30 family coping behaviors created from family stress and coping literature, which identified potential behaviors families may use to cope with TBI. A five point scale (1 = *never* to 5 = *almost always*), indicated the frequency with which the family used the behavior when faced with problems associated with head injury (Kosciulek, 1994a).

A multi-dimensional scaling (MDS) and cluster analysis were used to evaluate the structure of family coping with head injury. The use of cluster analysis in the study aided the MDS by locating groupings of similar data points. From the data obtained, the study examined three specific dimensions of coping; (a) individual-to-family versus family-to-community coping, (b) family respite versus head injury-focused coping and, (c) cognitive versus behavioral coping (Kosciulek, 1994). The results of the study revealed that family coping behaviors exist along these three dimensions, and the reflection of the cluster membership provides distinct interpretation (see Table 5, pages 67-69).

The first dimension in the study represented individual-to-family vs. family-to-community coping. Kosciulek (1994a) found that family coping behaviors at one end of this dimension (e.g., continued involvement in family activities and get togethers) involved efforts to achieve a balance between individual family members and its system. Listed at the opposite end of the first dimension, were coping behaviors

Table 5
Family Coping Behaviors, Coordinates in Three-Dimensional MDS Solution, and Behavior Cluster Membership

	Axis Coordinates			
_Cluster Family Coping Behavior Membership*	1	2	3	
Seek encouragement and support from friends	0.8045	0.2259	-0.1242	5
Continue family involvement in community activities	-0.0401	-0.7002	0.0015	3
Seek advice from others families who have faced similar problems due to head injury	1.9024	-0.2381	0.5011	4
Maintain a positive outlook about the family	-1.9845	-0.1778	-0.0076	1
Attend church services	-0.7140	-1.7590	-0.9386	3
Continue involvement in family activities and get-togethers	-1.9224	-0.2193	-0.1715	1
Be careful not to attribute all family problems to head injury	-1.2016	0.8694	-0.1897	2
Become actively involved in head injury advocacy (e.g., prevention, education, legislation)	1.8235	-0.4117	1.1290	4
Share problems with other family members	-0.4287	-0.0059	-0.2190	3
Take a break from the care of your member with the head injury	0.6931	-0.8165	-0.0454	3
Accept you family member with the head injury as he or she is and not dwelling on how he or she used to be	-1.9110	0.2959	0.3428	1

Table 5
Family Coping Behaviors, Coordinates in Three-Dimensional MDS Solution, and Behavior Cluster Membership (continued)

Family Coping Behavior	Axis Coordinates 1	2	3	Cluster Membership*
Seek information and advice from a doctor	0.7621	0.9786	-0.1537	2
Share concerns with neighbors	2.5726	-0.0905	-0.5557	5
Become assertive with your family member with the head injury, health care providers and insurance representatives	-0.0234	0.7002	0.4725	2
Believe you can handle the problems related to heady injury	-1.2561	-0.2450	0.0347	1
Seek professional help and counseling for family difficulties	2.2406	0.6118	-0.2085	5
Attend a support group for families who have a family member with a head injury	1.5474	-0.5719	1.7311	4
Express feelings and frustrations within the family	-0.1282	0.1539	-0.4120	3
Define problems related to head injury in a more positive way so that we do not become too discouraged	-0.7282	0.1858	0.3039	2
Seek services for our member with the head injury (e.g., rehabilitation, vocational)	-0.4520	1.3988	0.3682	2
Ask neighbors for favors and assistance	3.0270	0.0076	-0.3741	5

Table 5
Family Coping Behaviors, Coordinates in Three-Dimensional MDS Solution, and Behavior Cluster Membership (continued)

	Axis Coordinates			
Family Coping Behavior	1	2	3	Cluster Membership*
Try to understand the concerns of all family members	-1.4456	-0.0241	-0.0602	1
Accept stressful events related to head injury as a fact of life	-1.5010	-0.1773	0.1338	1
Learn more about head injury through reading, attending lectures, etc.	-0.4515	0.1010	0.7927	2
Continue to do things together as a family (involving all family members)	-1.5949	-0.0043	-0.3266	1
Believe that things will work out for the best	-1.6107	-0.1829	-0.3989	1
Seek advice from a minister	2.4471	-0.0938	-1.0985	5
Talk over personal feelings in the family	-0.4629	-0.2792	-0.3191	3
Encourage your family member with the head injury to be more independent	-1.8512	0.1895	0.4075	1

******Cluster membership:* 1=positive appraisal; 2=resource acquisition; 3=family tension management; 4=head injury reduction; 5=acquiring social support

Adapted from Kosciulek, (1994a, pp. 250-251).

directed at maximizing family-to-community approach (e.g., ask neighbors for assistance). Kosciulek (1994a) believes that:

> Because the long term care of a family member with a head injury calls for collaborative arrangement between the family and the larger community, a fit between families and friends, relatives, and social service agencies is necessary to achieve successful adaptation. Thus, consistent with family stress theory, this dimension is likely to represent a major dimension underlying family coping and head injury. (p. 253)

Family coping vs. head injury-focused coping, was the second dimension of the MDS. Family coping behaviors at one end of this dimension evolved around family efforts to seek relief from the constant care of their member with the head injury, whereas behaviors at the opposite end related to directly managing head injury specific demands (e.g., seek services for member with head injury).

The third and last dimension measured cognitive vs. behavioral family coping. At one end of this dimension were direct action behaviors aimed at reducing the number and intensity of the demands (e.g., become actively involved in head injury advocacy), whereas family coping behaviors were directed at improving the meaning of the head injury family situation (e.g., seek advice from a minister) and were located at the opposing end (Kosciulek, 1994a).

Kosciulek (1994a) observations are consistent with findings reported by others researchers (Brooks, 1984; Brooks & McKinlay, 1983; Kay & Cavallo, 1994; McCubbin & McCubbin, 1991; Rosenthal, 1984; Willer et al., 1991) when he states:

> The three dimensions underlying family coping with head injury identified in this investigation suggest that families most likely use a variety of coping strategies when attempting to manage problems and difficulties associated with a member's head injury. (p. 254)

While the findings of the research clearly indicate the use of multiple methods when learning to cope with a member's TBI, future research would be well served to follow and track behavioral case studies as well as the most effective coping strategies used by those participating in the investigation. The use of such tracking may enable families to utilize the strategies best suited for their needs without the trial and error that leads to weakened family attempts resulting in mental and emotional exhaustion.

Intervention/Coping Suggestions

In order to assist families in the areas of adaptation following TBI, Rosenthal (1984) proposed four categories of intervention strategies best suited for those families needing information and answers while learning to cope. These four strategies include: (a) patient and family education, (b) family counseling, (c) family therapy, and (d) family support groups. Patient and family education. Rosenthal (1984) believes that patient-family education is frequently ignored by health care professionals when working with TBI, and a strong need exists for many rehabilitation centers to create family education group programs. In noting the lack of services available for families with TBI he writes:

> In the case of spinal cord injury, families are often given brochures and reading material detailing the nature of spinal cord injury. However, this is not the case with brain injury because of the lack of widely available written materials or films on the topic. (pp. 237-238)

The family education model was previously described in chapter II including intervention techniques and recommended educational options. Rosenthal (1984) describes patient and family education as part of the routine of modern rehabilitation, yet rarely has it been utilized by the rehabilitation team. A significant number of complaints from families included the dissatisfaction with communication between themselves and the medical staff.

Recently, rehabilitation centers have recognized the need for family education and have developed specialized patient and family education groups. These group sessions are designed to provide the basic information about the nature of brain injury and its consequences and to help families gain a greater understanding of the stages of disability and rehabilitation (Rosenthal, 1984). The ten educational sessions are usually 1-to-2 hour meetings spread out over a period of 5 weeks and are held in the evening to gain maximum family attendance. A combination of lecture and discussion is mixed with demonstrations, coping techniques, and audiovisual aids on TBI and family adaptation. This method of intervention has been well-received and will benefit most families in the early stages of recovery from brain injury (Rosenthal, 1984).

Family counseling. Family counseling is described by Rosenthal (1984) for the purpose of allowing rehabilitation professionals, usually initiated by a designated member of the rehabilitation team, to assist the family in understanding and accepting the disability and its potential consequences (e.g., increased dependence, impaired cognitive and behavioral functioning, decreased physical abilities). The precise timing of this service is debatable due to the varying needs and desires of the individual family.

Hegeman (1986) describes the phases families go through as high anxiety, denial, remorse, grief, and reconciliation. She also notes that despair is a phase frequently seen in the rehabilitation setting, and this must be included in the pre-counseling assessment. Hegeman (1986) further maintains that:

> Family members are not at the same phase at the same time. Family members at different phases may be able to give support to each other; however, these differences may also cause discord, chaos, and disunity in the family. (p. 261)

The counseling sessions suggested by Rosenthal (1984), allow the family members (often the parents or a spouse of the patient) to express their feelings of guilt, anguish, sadness and loss. This provides a time for questions about the nature of the disability, its prognosis, and the level of care required for the injured family member. The counseling helps families regain some balance and prepare the family members for the experiences they may face.

Rosenthal (1984) describes the effects of family counseling in assisting the coping process as follows:

> Uncertainty regarding appropriate management techniques can often lead to inconsistency and feelings of guilt and inadequacy. Maintenance of ongoing contact in periodic family counseling sessions can help minimize the deleterious effects of these problems and their disruptive impact on the family. (p. 240)

Counseling can be indirect and nonthreatening with family members knowing that it is a safe place to work on issues that are often skipped during the trauma of dealing with their injured family member. Kay and Cavallo (1994) describe the counseling process as being comprised of support, problem solving, and restructuring. They see the counselor as an active therapist who knows the realities of adjusting to brain injury, and builds on the existing strengths and problem solving capacities of the family and individual members. Rosenthal (1984) views counseling as a way to prevent the experience of overwhelming disappointment and frustration. The counselor gently prepares the family for the realities of life with a brain injured relative and provides support during the most difficult transition periods (Rosenthal, 1984).

Family therapy. Rosenthal (1984) lists family therapy as essential in assisting the family during the difficult stages of post injury release of its TBI family member. The chief objective of family therapy is to alter maladaptive communication and interaction patterns within the family system. Bond (1979) agrees with this goal when he informs:

> Family therapy or group therapy with family members should be continued throughout all stages of recovery although the details of therapy will differ at each stage. (p. 158)

By doing so, active intervention and coping can progress since family therapy focuses on the entire family and not just on the brain injured person.

Rosenthal (1984) lists goals of family therapy as including, but not limited to:

1. To provide a supportive environment where all family members can freely verbalize feelings about the trauma and its effects upon the family.
2. To educate the family about the nature of the deficit in communication and interaction and develop methods for resolving conflicts within the relationship patterns of the family system.
3. To examine and clarify role relationships and restructure roles and responsibilities within the family system. The use of family therapy does not guarantee a workable solution to the coping and adaptation phase since many families could be resistant to or fearful of additional burdens following post injury release of the patient. Therapy of this type is best initiated prior to discharge, but usually is ignored until problems arise and the family is at the end of its patience with the injured member and the changes caused to the family's life (Ross et al., 1983).

Rosenthal (1984) lists specific techniques that can be employed in family therapy, and these include:

1. Emphasizing the mutuality of responsibility for the maladaptive communication and interaction within the family-shifting the burden of guilt and blame from the identified patient to the family system.
2. Analyzing and emphasizing the positive aspects of the family system-reinforcing evidence of appropriate and healthy interaction that occurs within sessions.
3. Exploring the dysfunctional patterns of interaction by reenacting family conflicts and assisting family members in problem solving to alleviate conflicts.
4. Prescribing "homework assignments" for the family to practice outside the sessions so as to foster generalization of behavior change. These tasks may include altered methods of communication between parent and child, specific problem-solving techniques to employ when conflicts arise, or perhaps alternative and more adaptive ways of expressing feelings and frustrations.

Family support groups. As discussed by Rosenthal (1984), family support groups have been defined and examined in chapter II. It is important however, to mention the use of support groups as being highly touted by researchers (Mauss-Clum & Ryan, 1981; Rosenthal, 1984; Watson, 1987) as an essential element in the coping and adaptation phase that families coping with TBI go through. Kaplan (1991) defined support groups as a multidimensional construct with emotional, cognitive, and instrumental or tangible components and deduced that:

> A broad base of evidence suggests that social support directly buffers the delirious effects of stress and anxiety, and directly contributes to psychological well being across a wide range of population and research groups. (pp. 361-362)

Kosciulek (1994b) recognized that participation in support groups dramatically reduces the demands on family members through education and sharing experiences. Rosenthal (1984) reflects that many families do not feel comfortable with health care professional and for a variety of reasons, considers support groups as the ideal resource. Understanding the impact of support groups led Rosenthal (1984) to state "... the notion of peer counseling and support has gained prominence within the field of rehabilitation" (p. 242). The sharing of experiences and unconditional support of others facing the similar trauma of TBI, allows members to develop a relationship that lasts far beyond that of rehabilitational professionals and at little or no cost.

Support groups strengthen many families and help create an enduring bond that is apt to be eliminated as a result of the TBI. Kaplan (1991) perceived this when he indicated that:

> Support groups are an example of explicit social support that can be provided for both the injured person as well as significant others. Lezak and many others have advocated the use of group support to ease and share the long term emotional burden of living with a brain injury. (p. 367)

In a similar vein, Rosenthal (1984) concludes that:

> To date, studies have not been conducted demonstrating that family intervention significantly alters the ultimate prognosis, outcome, and quality of life for the brain injured victim. However, there is an increasing body of evidence suggesting that family intervention should be considered as primary rather than secondary or optional mode of treatment in comprehensive rehabilitation management of the brain injured patient. (p. 245)

CHAPTER IV

CONCLUSIONS AND SUMMARY

The purpose of this thesis was to (a) briefly describe the dynamics of TBI that most commonly affects the family including: injury characteristics, personality changes, psychosocial implications, and the impact of TBI on the family; (b) research and summarize the literature that pertains to the impact of TBI behavior; (c) review and offer suggestions for families and counselors working with the injured patient and with each other; (d) review published empirical studies on specific support interventions that address family adaptation and coping methods for those who are facing TBI; and (e) review relevant TBI materials designed to measure effective coping strategies, as well as future considerations for researchers studying the family and TBI.

Impact of TBI on the Family

The literature clearly indicates that TBI adversely effects the lives of millions of people each year with financial costs to taxpayers, insurance companies, and most importantly, the emotional costs to the families of these persons. Despite statistics that indicate a growing trend in the numbers of people sustaining a severe head injury, little has been done, in comparison to other disabling conditions, to assist families in coping. Hence the phrase "the hidden epidemic", in the description of many health care professionals responding to the millions of people suffering from TBI and the families who support them.

Families caring for TBI patients in comparison to survivors of other types of long-term disabling conditions (e.g., spinal cord injury), experience longer duration of patient dependency and stress. The family, is often forced into caring for their TBI relative with little or no insight into the cognitive and behavioral changes that occur both immediately following the accident, and those that occur over time. Researchers (Brooks, 1984; Brooks et al., 1986; Brooks & McKinlay, 1983; Oddy et al., 1985), have determined that these changes in the patient often become worse and more pronounced over time.

Families of TBI patients have a tremendous need for ongoing support and education, both immediately following the injury, and in the years to follow. Families and relatives may feel overwhelmed by the TBI, and may be unable to (a) accept the long term effects of the disability; (b) implement proactive interventions following the head injury; (c) understand the patient's newly imposed limitations; (d) provide the necessary support for the injured member and give up; and (e) utilize special counseling and therapy that allows the family members to discuss options, vent feelings, and seek support.

Research suggests that certain high risk indicators of family stress prior to patient injury, comprise the greatest risk for problems with coping and adapting to TBI (Brooks, 1984; Rosenthal, 1984). Families, with the use of identified intervention models, are much more likely to successfully adapt and utilize coping methods for both the injured member and themselves in dealing with the unpredictability of lifestyle changes. While a majority of the existing literature on TBI pertains to symptoms and long-term consequences resulting from head injury, very little information exists on how families are expected to cope and adapt to this life altering experience.

The literature suggests that lifelong struggles to adjust to TBI are as difficult for the family, if not more, than for the injured member. The investigations of lifelong sequelae following TBI has dominated research in the past, with a recent surge in family considerations becoming more evident. Rehabilitation professionals continue to grapple with specific methods of coping for the family, often conducting pilot studies that relate to management of family stress. These studies, while useful, rarely reach those who need the information most and often go unnoticed by families unable to easily obtain the information or understand it.

Recommendations for Future Research

The escalating interest in TBI research suggest that there is much to be learned from the families living with an injured member in day-to-day contact. In some of the outlined TBI intervention strategies, there exists an almost unrealistic expectation, that families can simply use one generic strategy for a specific need (e.g., seek advice from a relative, accept the injured family member as he or she is). This belief, that one size fits all, inadequately addresses the uniqueness of the families dealing with individualized situations and conditions. Many considerations have been neglected in the development and design of the research and literature pertaining to TBI in the family. Among them are: (a) socioeconomic factors; (b) religion; and (c) cultural differences to name a few.

Since interventions can be modified and developed for individual needs, researchers need to clarify these individual intervention models with rehabilitation professionals and families looking for the intervention that is "tailor made". Despite the efforts of researchers, attempts to define what interventions work best with what group are often inconsistent, only the listings of "high risk" families is mentioned in the research based on family stability prior to head injury. In addition, research conducted by medical specialists on the effects of TBI often report out of date information based on the experimental investigations completed by others decades ago. These studies often describe cognitive and behavioral changes as physiologically predictable, suggesting that head injury outcome can be measured similarly to those of other physical disabilities.

Rosenthal (1984) gives an example of this line of research when he writes:

> As discharge approaches, families become apprehensive, since they have been given an implicit or explicit message that a "plateau" has been reached. During the transition from hospital to community, the counselor can play a key role in assisting the family to anticipate future problems and be more psychologically and physically prepared to assume the burden of care. (p. 239)

Willer et al. (1991) discovered in their research, that this is not consistent with the realities of families facing TBI when they write:

> Recovery from TBI is said to follow a predictable course, loss of consciousness, PTA (post traumatic amnesia), rapid recovery, and plateau. The accounts of husbands and wives who attended the retreat weekends argue against this description. First, they reported that their own recoveries were anything but predictable; second, they did not feel that a plateau phase was ever reached. The use of the word "plateau" by rehabilitation professionals was widely criticized by the participants. (p. 64)

Contradicting assessments of what investigators perceive as normal remain evident since intervention focus is rarely similar to those expressed by what the family needs. It appears that the most successful intervention strategies are those defined by families having experienced the implications of TBI. Only through the use of follow-up studies and ongoing research attempting to understand the family experiences in TBI, will questions of coping and adaptation be answered. Instruments developed to measure family stress to crisis do exist (McCubbin & Figley, 1983; McCubbin & McCubbin, 1991) but these do not seem specialized enough to assist the TBI family members in adequate fashion. Kosciulek (1994a) confirms this belief when he writes:

> Future research should also include the development of a useful instrument for measuring family coping with head injury. Head injury rehabilitation and family therapy professionals would find such an instrument valuable for guiding family assessment and intervention. Finally, longitudinal research on family coping offers the best hope for understanding family adaptation to a members head injury. (p. 255)

Kosciulek (1994b) advocates for the use of longitudinal research in a similar review when he advises:

> Profiles of families most at-risk and resilient to the demands of head injury should be developed through investigations focusing on family coping over time. Such profiles could then guide clinical family intervention, the development of family support services, and policy decisions. (p. 226)

Most of the studies indicate a clear trend toward working with families who are suffering from shock, but become more adept at coping through sheer will and initiative. Perhaps, additional research could be geared towards families with those groups who are less autonomous or more inclined to passively accept little or no intervention strategies. Ross et al. (1983) believe that families who are less autonomous are less likely to seek long-term support and are therefore incapable of internalizing interventions to the point of becoming self-managing. Furthermore, there has been no systematic study in the literature of which relationships are more vulnerable to the stresses imposed by head injury persons (Livingston, Brooks, & Bond, 1985).

In addition, a useful and reliable instrument to measure the psychosocial adjustment to TBI would be well served in assisting the rehabilitation professionals, patient, and family. The importance of investigating psychosocial outcomes has been documented to affect the rehabilitation planning and long-term acceptance of perceived disabilities, yet few instruments exist that can adequately predict needs beyond those that are physically evident.

Livneh and Antonak (1994) support this observation when they argue:

> The lack of a psychometrically sound multidimensional instrument to measure psychosocial adjustment to specific disabilities continues to be a deficiency. Instruments to measure psychosocial adjustment need to be periodically refined and improved by their authors. (pp. 68-69)

Finally, since reintegration and acceptance are so strongly linked to family cohesiveness, one could clearly assume continued research with support groups and their long-term effectiveness be examined in the years to follow. If a broader, more comprehensive understanding of the reintegration process is to be obtained, researchers must direct their attention to examining the effects of social support (e.g., support groups) on the process of adjustment (Kaplan, 1991). The adjustment process that includes support groups could attempt to provide more than merely information and a feeling of security for its members. Kaplan (1991) suggests more need for social support exploration when he explains:

> ....research is needed to determine how to social support might be systematically wedded to supported employment, and how it may be most expeditiously introduced into the total rehabilitation process. Research is also needed to determine more specifically which aspects of social support expressly work to improve the outcome status of persons with severe TBI. (p. 367)

Research Related Comments

It would be a daunting task, to one day know all the answers and strategies for assisting families facing the daily crisis of TBI. Until research and the collaboration of information and professional opinion intersect with family needs, coping and adaptation will be slow to understand. The uniqueness of each TBI continues to baffle the rehabilitation community, who like the families it affects, has no simple remedy for a cure for their specialized problems.

Realistically, it should not be assumed that all family members will adapt to or effectively cope with the loss of their injured members former self. In a similar vein, Wortman and Silver (1989) responded: "... contrary to popular belief, individuals are not always able to achieve resolution regarding their loss..." (p. 353). Families facing the obstacles of coping and adaptation want and need concrete solutions and instructions to effectively deal with the TBI person and sudden life changes. Unlike medical treatment that can often cure or lessen the pain of many disabling conditions, TBI characteristics remain as elusive as other riddles of the human mind. In 1962, John F. Kennedy remarked "The greater our knowledge increases, the greater our ignorance unfolds" - such remains the case in the total understanding of TBI, there is still an immense amount of knowledge to be obtained.

A review of the literature should not be a lighthearted jest at the years of work put forth by many dedicated professionals who have sought answers to many questions, for even their educated opinions assist in the opening of doors that have been sealed for years. In 1644, John Milton said "Where there is much desire to learn, there of necessity will be much arguing, much writing, many opinions; for opinion in good men is but knowledge in the making" (Bartletts Familiar Quotations, 1992, pp. 254-255). - such should be the belief of those attempting to unravel the mystery of coping with TBI.

Ultimately, the answers to family coping and adaptation will remain as individualistic as the families requiring the assistance and direction. Finding the intervention that best fits each level of need, using the information we now have, seems like a natural fit. Ideally, through the labors of research, more answers will be found to help families determine their exact needs to cope effectively. It is only through the continued attempts to understand TBI that we have learned to treat its symptoms. Hopefully, the same can be said for the families with the passing of time.

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