FAMILY ADJUSTMENT TO THE LONG TERM EFFECTS OF TRAUMATIC BRAIN INJURY OF HUSBANDS

This paper represents the first summary report of a weekend retreat for families affected by brain injury to husbands. The intention of this paper is to describe the experiences of these families from the perspective of the husbands with disabilities and their wives. Extensive data was gathered on each family and, once this data has been analyzed, the results may very well differ from the perspectives of these wives or husbands. However, we feel that their own accounts of the problems and helpful aids arrived at by their families should be presented on their own.

It has often been stated that when one member of the family becomes disabled, all members of the family experience the disability in one form or another and all members of the family must cope with the effects. The literature on families of individuals disabled by traumatic brain injury has demonstrated this fact time and again. Lezak (1988) describes the emotional and practical burden felt by the primary caretaker. Usually caretakers are family members who may even be forced to give up their jobs or other pursuits so that the disabled family member receives the best care and treatment in the home or elsewhere. Lezak cites previous research, which has found that caretakers (most often wives and mothers) are likely to experience significant depression within the first year after injury.

The burden and stress felt by family members is strongly related to the behavioural and characterological alterations which are often displayed by individuals with traumatic brain injury (Brooks & McKinlay, 1983; McKinlay, Brooks, Bond, Martinage, and Marshall, 1981). Instrumental burden associated with providing assistance because of the individual’s physical limitations appears to be less debilitating than the emotional burden associated with behavioural sequelae. At least one other source of burden reflects the family’s worry about the patient’s future care and outcome (Oddy, Humphrey, & Uttley, 1978).

The stress of caring for a family member with an injury can actually impact on the health of the caretaker. Livingston, Brooks, & Bond (1985) found anxiety to be a major problem for the caretakers of brain-injured men, one year post injury. Brooks, Campsie, Symington, Beattie, & McKinlay (1986) interviewed their sample five years
post injury. With the exception of a slight increase in aggressive behaviour, the head injured individual’s problems did not change noticeably. However, caretakers reported significantly greater levels of stress when compared to one year post injury. This may indicate that factors other than the disabled individual’s symptoms account for the caretaker’s eventually become exhausted by the demands imposed upon them.

Other changes to the family result from the disability experienced by one of its members. Research has described social role changes and interpersonal disturbances. In a study by Rosenbaum and Najenson (1976) wives of head injured Israeli war veterans experienced greater role change and distress than wives of paraplegic veterans. The women of the head-injured men reported a decrease in leisure time, fewer contacts with friends and greater disruption of their marital relationship. They also felt less able to share household, childrearing and financial responsibilities and loss of enjoyable social activities were associated with depressed mood in the wives.

**STRESS REACTIONS OF WIVES OF DISABLED HUSBANDS**

Livingston, Brooks and Bond (1985) studied the burden and changes in role functioning of wives and mothers of individuals with traumatic brain injury at 3, 6 and 12 months post injury. They found no significant differences between wives and mothers although there was a trend toward increasing levels of burden among the wives over time and decreasing burden among mothers. The study also indicated impairment in marital role functioning of both mothers and wives when compared with the norm. Unfortunately, the study does not report on the statistical significance of this finding nor does it indicate the marital status of the mothers.

Rosenbaum and Najenson (1976) conducted the only study that specifically looked at the burden and reactions of wives of individuals with traumatic brain injury. As described earlier, the subjects were the wives of Israeli soldiers. The results point to the stress reactions of the wives one year post injury and the authors conclude that the wives experience a clinical crisis period one year following injury. While instructive, the study did not examine the long term reactions of wives or how they adapted to the changes in their husbands and family life. In addition, there are obvious cultural and situational differences between wives of injured war veterans in Israel and the North American wives of individuals head injured accidentally.

The research to date on family response to traumatic brain injury is useful but has several important limitations. The research is generally limited to the first months or year post injury when disruption in the family is greatest and families are likely to be experiencing crisis. Although this is important, it provides little guidance about long term problems or how families cope. Another limitation is that while most individuals with brain injury are male and most family care providers are the mothers, the studies have tended to treat wives and mothers as one and same. There appears to be little recognition of the fact that coping with a disabled husband may be vastly different than coping with a disabled son or daughter. Fathers, husbands and children of individuals disabled by brain injury have rarely been studied.

**THE PERSPECTIVE OF DISABLED INDIVIDUALS**

Another limitation of the research to date is that little is known about the perspective of individuals with traumatic brain injury. Individuals with severe head injuries usually exhibit cognitive and behavioural disabilities many years after the injury (Thomsen, 1984, Brooks, 1984, Brooks et al., 1986). Typical problems include: attention and concentration deficits, difficulties with planning activities, impulsivity, communication deficits, memory and information-processing deficits, judgment and perception difficulties (Prigatano and Fordyce, 1986). According to the literature, these disabilities are the greatest obstacles to employment. They are also viewed as the greatest

Much of the research on behavioural sequelae and psychosocial effects of traumatic brain injury has depended on interviews with the individual’s family member or a professional staff person or both. Thomsen (1984) conducted a fifteen year follow-up on individuals with traumatic brain injury and obtained observations on adjustment from family caretakers, professional treatment staff and the individual with disabilities. Although this was one of the few follow-up studies to examine the perspective of the disabled individual, the research design indicated that "The patients were interviewed by a similar but not identical questionnaire. When the two statements did not agree, the relative’s or staff’s answers were preferred" (p.261).

Researchers have relied on relative’s impressions because of the presumed loss of insight that accompanies cognitive disabilities. The literature has noted that this loss of insight is characterized by an inability to monitor one’s own behaviour, to perceive the effect that it has on others and to adapt to changing social cues (Wood, 1987). This is also presumed to affect the ability of the individuals to accurately report on the difficulties they are experiencing.

Research has examined the level of agreement between head injured individuals and their relatives on post-injury impairment. McKinlay and Brooks (1984) interviewed the individual and the relative and found that there were systematic differences between the two reports. In terms of sensory and motor impairments, agreement was found on behavioural and emotional characteristics. However, this study looked at individuals six months after brain injury and may not apply when further recovery has had a chance to occur.

Elsass and Kinsella (1987) examined self-perceptions of subjects with severe closed head injury. They compared fifteen individuals’ self-reports with their family members’ reports. They also examined the level of agreement between a matched sample of fifteen non-head injured individuals and their family members. The researchers found that individuals with traumatic brain injury were significantly more likely to have behavioural disturbances when compared with their matched controls. However, the individuals with disabilities had the same level of agreement about the presence of problem behaviour with their family members as the matched controls. The authors conclude that individuals with brain injury appeared to be aware of their own behaviour and limitations.

This current paper describes the results of group discussions with husbands disabled by traumatic brain injury, and their wives. The focus of the group discussions was the problems faced by the individuals and the family. A second focus was identification of coping strategies found to be effective. These issues were examined from the perspective of both the disabled husbands and their wives.

**METHOD**

**THE ONTARIO BRAIN INJURY ASSOCIATION (OBIA), IN BRAIN INJURY ASSOCIATION FAMILY RETREAT**

collaboration with researchers at the University at Buffalo, Research and Training Center on Traumatic Brain Injury, decided to investigate the long term coping strategies of families by holding a series of weekend retreats. The first retreat was held in St. Catharines, Ontario and twenty families were invited to come and talk about their experiences. These twenty families had one important characteristic in common; the husband was disabled by traumatic brain injury.
The extent to which brain injury is a family affair is demonstrated by the number of individuals represented by these twenty families. There were 20 husbands, 20 wives and 41 sons and daughters. Several families also talked about the effects of the disability on relationships with in-laws and grandchildren. The lives of many were affected by the injury and resulting disabilities of each of these men.

The average age of the husbands and wives was 39. The age range was 21 to 61 among the wives and 22 to 55 among the husbands. As a group, the twenty couples represented 289 years of marriage. The average was 14 years but the couples ranged from 2 years to 32 years of marriage or co-habitation. All but two couples were married at the time of the injury.

All of the men were severely brain injured. They had a post traumatic amnesia period of 7 days or more. The time since injury ranged from one and a half years to eighteen years, with the average of four and a half. The causes of the injury included auto accidents (n=10), being hit by a car as a pedestrian or bicyclist (n=3), falls (n=2), industrial accidents (n=2), motorcycle accidents (n=2) and one airplane crash.

Announcements about the retreat were distributed to all southern Ontario chapters of OBIA. The announcement described the retreat and invited interested families with a husband or wife with brain injury to contact a toll free number. Approximately 40 families contacted OBIA and requested to participate. Some had head injured wives and will be considered for the next retreat. Some included wives or husbands recently injured and struggling with different issues. Some included husbands who had not experienced a blow to the head resulting in brain injury and therefore did not technically qualify as traumatic brain injury. Some were over the age of 60 and a weekend for the elderly head injured is being considered for a later date.

The first twenty families who applied and qualified for the first retreat were invited, and all twenty attended. The families came from various cities and small towns in southern Ontario although very few families came from the same city. Traumatic brain injury is much more common among unmarried individuals (Gale, Dikmen, Wyler et. al., 1983).

Husbands and wives were told that the primary purpose of the retreat was to gather information about their experiences with traumatic brain injury. For this reason the transportation, food and lodging costs were assumed by the University research project. Husbands and wives were asked to complete a number of questionnaires. The characteristics of the individual and family assessed by these questionnaires included:

1. The disabilities and handicaps of the husband with traumatic brain injury
2. The disabilities and handicaps of the wife
3. The cost of traumatic brain injury to the family
4. The effect of disabilities of the husband on his role as a father and his relationship to the children
5. The effect of disabilities of the husband on the marriage
6. The level of satisfaction and community integration of both husband and wife.

The questionnaires which assessed each of these characteristics were selected because they had been used previously to assess individuals and families with disabilities. Some were specifically developed to assess individuals with traumatic brain injury.

The procedure of administering individual questionnaires used on the family retreat is standard to all research investigations. Data on individuals and about families is gathered from individuals and analysed using appropriate statistical techniques, testing various hypotheses. However, we also wanted to ask the subjects (husbands and wives in this case) what problems exist and what have you done that works?
THE NOMINAL GROUP TECHNIQUE

In order to ask the questions about problems and solutions in a systematic manner, we used the nominal group technique (Delbecq, Van de Ven & Gustafson, 1975). This is a highly structured approach to group decision making, whereby a single question is posed to the group, answers to the question generated and written down by each individual and then recorded in a manner that allows all group members to view, clarify and finally rank order all answers.

The nominal group technique forces each participant’s involvement but does so in the least threatening fashion. For example, the individual who generated an idea is not asked to defend or clarify the idea to others. All ideas generated are viewed as the product of the group and therefore clarification is the responsibility of all group members.

The technique is most effective when limited to groups of ten or fewer individuals and where group members share some common background or experience with the issue being discussed. For this reason, the twenty couples were divided into four groups, each consisting of 10 husbands or 10 wives. The wives and husbands were separated according to whether or not they had children currently living in their home.

The groups met twice, once to identify family problems associated with traumatic brain injury and second, to identify coping strategies that helped to reduce the magnitude of these problems. The following is a summary of the results of the (disabled) husbands’ perspectives on problems and solutions, followed by the wives’ perspectives on problems and solutions. Differences in conclusions and priorities between the two groups of husbands were minimal; the same can be said for the two groups of wives.

RESULTS

PROBLEMS IDENTIFIED BY HUSBANDS WITH TBI

1. Loss of independence
2. Loss of role of husband, father and provider
3. Difficulties associated with recognizing and adapting to their limitations
4. Loss of memory

The main problem identified by the husbands was the frustration of losing their independence. Some men had a motor disability which impaired their mobility. Some had lost their driver’s license. Many felt that they were often being “baby-sat.” The men expressed frustration at having tasks done for them; they wanted to try the tasks for themselves.

Another aspect of the loss of independence centered on the role changes in the household. Their wives had taken on responsibilities that, before the injury, had been their husbands’. These men stated that they felt castrated; that their manhood had been taken away from them. Additionally, several of those who had children felt that their sons and daughters were being asked to grow up too fast; the children were asked to take on responsibilities beyond their ages.

Accepting the new limitations was difficult for the men. The injury had reduced their skill levels. Tasks found to be simple prior to the injury were now complex and required much more energy to complete. Many of the men were unable to go back to their pre-injury occupation. The few that were employed were now in occupations of less prestige or importance. A few were working without pay on a trial basis.
One of the major limitations reported by these men was the loss of memory. Remembering an appointment, a birthday or a shopping list could no longer be taken for granted.

Some of the men tended to place more emphasis on problems that were concrete, such as the loss of income or difficulties in walking. Some were more concerned about interpersonal problems such as changes in the relationship with their wives. The majority of these men seemed to be aware of the impact of their disability on themselves and their families. Some of these men were surprisingly capable of expressing their feelings for others. During the group discussions the men were also considerate and patient with those whose communication skills were limited.

**SOLUTIONS IDENTIFIED BY HUSBANDS WITH TBI**

1. Being included in family decisions
2. Understanding the concerns of other family members
3. Involvement in activities outside the home
4. Development of a realistic appraisal of their limitations
5. Use of organizational and memory aids.

The men found that one of the most helpful ways of dealing with injury was to be understanding of their spouses’ feelings and hurts. Ongoing communication with their spouse helped to facilitate this understanding. They found it helpful to talk things over with their wives so that they could make decisions together.

Other helpful strategies included doing volunteer work and trying to get back the activities that had been lost, such as driving, sex, sports, work, laughing and crying. The men found it very helpful to be involved in activities that took them out of the home.

The men also stressed the importance of having a clear idea of their abilities and limitations. A realistic appraisal meant knowing what they could do, as opposed to what they would need others to do for them. Understanding their abilities and disabilities gave them the courage to ask for assistance when necessary. A realistic appraisal enabled them to take responsibility for their own actions, rather than relinquishing all responsibilities to someone else, such as their wives.

To adapt to their memory impairment the men used uncomplicated technological aids (e.g. alarm watches, telephone devices and calendar books) or wrote down whatever they needed to remember. This became evident to us during the group process. While discussing the ideas that the group had generated, the men were busily writing. We immediately thought that they were copying the lists from the charts. They were told that they did not need to write all of this down, as we planned to copy and distribute it to them. The men enlightened us by explaining that they were not copying the charts, rather, they were writing down ideas that they did not want to forget.

**PROBLEMS IDENTIFIED BY WIVES OF DISABLED HUSBANDS**

1. Changes in husband’s personality
2. Changes in husband’s cognitive abilities, including memory loss
3. Husband’s lack of insight and acceptance of his disability
4. Reduction in financial resources
5. Loss of emotional support, sharing and companionship
6. Feeling unable to meet children’s needs

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One of the major difficulties experienced by the women was the personality changes displayed by their husbands. These changes were so dramatic that many women stated, “He isn’t the same person I married.” The wives felt burdened and stressed, in part, because they felt obligated to care for a man whom they consider to be a stranger.

The cognitive sequelae of traumatic brain injury, such as memory loss and the individual’s lack of insight about his disability, were reported to be problematic and sometimes required the wives to be extra vigilant. For example, problems of forgetfulness, forgetting where one lives, forgetting medications or forgetting his limitations, require these wives to be constantly on guard.

Many women reported that their personal energies and resources had been pushed to the limit. The wife had little time for herself. These wives felt isolated, lonely and misunderstood. In some cases, the individual with the injury is able to function well in social situations, but gets angry and irritable at home. Friends and relatives who do not observe the inappropriate behaviour tended to minimize the wife’s complaints. In some cases relatives reduced or avoided contact with the injured individual and the family.

Income is lost during the disabled individual’s recovery and rehabilitative period. In most cases these wives were dealing with an uncertain financial future. Few expected their husbands to return to work. Financial resources were also reduced when the wife gives up employment in order to be at home to care for her husband. The costs of care and treatment, the loss of income and the reduced savings are major concerns.

The wives reported that their children were often confused and frightened by the changes they saw in their father. Although the children may require extra attention, the wives reported being too busy caring for the husband to meet the children’s needs. Some of the husbands’ behaviour such as outbursts, were seen as particularly problematic for the children. The wives reported feeling caught in the middle between the husband and the children.

The most significant change reported by these women was the loss of companionship and emotional support that they had previously received from their husbands. Some women described the accident as having taken away their best friend.

**SOLUTIONS IDENTIFIED BY WIVES OF DISABLED HUSBANDS**

1. Developing a realistic but optimistic outlook
2. Becoming assertive with disabled husband, health care providers, in-laws and insurance representatives
3. Allowing husband to be independent
4. Taking time for one’s self, away from one’s spouse
5. Going on family outings and spending enjoyable time together as a couple or a family
6. Participation in support groups

The wives of men with traumatic brain injury identified several activities and philosophies which helped them to cope with the changes that occurred in their lives. First, most of the women stated that it was very helpful for them to be optimistic. While they had to learn to be realistic and realize that their husbands will never be the same, they had to develop an understanding that recovery from brain injury is a long process. Many had now come to realize that their husbands will continue to improve for years after the injury. A few described how a good neuropsychologist and other hospital personnel were important in helping them learn about the realities of brain injury.
Many of the wives learned that it was important to assert themselves with family, friends, medical Personnel, bureaucracies and their husbands. They reported having to set limits with their husband, giving him honest feedback and allowing him to be involved in decision-making. In this manner, the individual with the disabilities is given greater responsibility for his behaviour and his family. The wives also found that relations with in-laws and friends improved when they developed a take charge attitude.

It was useful for both husband and wife to give the husband specific household responsibilities e.g. cooking, cleaning etc. Although this sometimes caused added difficulties for women (initially it was much easier to do everything themselves) they realized that their husbands needed to regain their self-esteem. This can be achieved through adoption of new roles within the family and household. The alternative is to have the husband simply assume a passive, dependent role.

The wives also felt that it was important to encourage their husbands to get involved in other meaningful activities, such as hobbies. For many of these individuals, return to gainful employment was out of the question. Wives were able to describe how various hobbies and outside activities had helped to restore self confidence in their husbands.

These families found it important to schedule pleasant family outings and enjoy each other’s company. Conversely, these women also recognized the necessity of making time available for themselves and attending to their own needs. Many described the value of returning to a favourite activity such as an aerobics class or their job. Several women reported on the benefits of individual counselling.

One of the most beneficial resources identified by these women were support groups. The women felt that others who also have a disabled spouse can best understand what they are experiencing. Support groups provide their members with the practical advice, understanding and comfort that is not available elsewhere. In essence, support groups help their members feel less isolated.

**SUMMARY AND CONCLUSIONS**

In a matter of a few seconds, a person’s life can be inexorably changed by a blow to the head. When this happens it changes the lives of many. These families were able to provide very personal accounts of the changes, the frustrations, the pain and the accomplishments. Each family had developed coping mechanisms that worked for them but may not be generalizable to others. All demonstrated, however, the tremendous strength of the human spirit.

The process of selecting and studying families that volunteer through an announcement by the Brain Injury Association chapters creates an uncertain sampling bias. We assume that families motivated to cope with the disability were more likely to volunteer. Wives convinced that their marriages would fail would not volunteer or might not be members of the Brain Injury Associations in the first place.

Even with this bias, we found there was so much to be learned from these families.

We learned that men with traumatic brain injury have a great deal to say about the circumstances of their lives. Contrary to our expectations, these men were generally aware of the changes that had occurred for them and their families following their accident. In general, they seemed aware of the impact of their disabilities on other family members and expressed guilt for the demands now placed on their wives. They talked of the fact that their wives had assumed many of the responsibilities previously managed by themselves. They also mentioned that their wives now had to tolerate their outbursts and dependencies.
We also learned that these men want to experience the dignity of risk, i.e. they want to be allowed to do things for themselves. Even if they might fail they want the opportunity to try. They want to experience the self-esteem that comes from attempting to manage one's own life. Self-esteem and self-confidence are features of their lives that were reduced, not by the brain injury, but by the consequences of losing one's job, one's roles within the family and one's manhood. They felt that these losses would only be overcome if they would be allowed to experience success and failure on their own.

These men were at different stages in their adjustment process. Some were more concerned with overcoming physical limitations, while others were beginning to examine quality of life issues. When posed with the question of what effects traumatic brain injury has had on their families, their answers mostly reflected on themselves. There was also mention of the impact on their wives. The most helpful advice they might offer is to learn about one’s limitations and try to accept them and never give up. These men greatly resented the word plateau, a phrase commonly used by rehabilitation specialists implying that all recovery has been reached and no further progress can be expected.

The coping strategies developed by these men were interesting, especially since very few of them had the benefit of sophisticated rehabilitation programs. Many had not received rehabilitation at all. (Ontario has few rehabilitation programs for brain injury now and even fewer at the time most of these men experienced brain injury). However, most of these men had developed various strategies for memory assistance. They were almost all chronic note takers. Many had calendar books, alarm watches and tape recorders for this purpose.

Another common theme in the adjustment process was the value of meaningful activities, especially if it got them out during the day. Volunteer work was frequently mentioned. Their advice was, “Get out of the house and out of your wife’s hair”. The men caution, however, that energy levels are not what they once were and that they needed to be alert to fatigue and resulting outbursts and mood shifts.

The wives experienced tremendous upheaval in their family life at the time of injury. They described the extraordinary time and energy committed to the needs of the husband. They also described the effort required to recover some semblance of stability in their families. To accomplish this without the assistance and moral support of the one person they relied on most, their husband, added to the strain they experienced.

Many wives reported a sense of isolation as friends and relatives are sometimes unable to understand what has happened to their lives. It is difficult for others to understand that just because their husband looks and acts in a normal way that the problems of judgment, memory or behaviour cause considerable disruption, especially if there are children in the home. Some wives described their husband’s return to the family after the accident as the addition of another child.

Family income is frequently reduced. Some wives find they must seek employment to make ends meet. Others reported giving up their employment because of the needs of the husband. Most must take over many of the husband’s responsibilities, such as financial matters, at a time when finances may be the most complex. Many were involved in litigation on behalf of their husbands.

The wives were able to describe the person they felt compelled to become to successfully cope with changes in the family that result from the disabilities of their husbands. She must be assertive, to be able to manage the husband’s moments of depression or frustration, to deal with unforgiving insurance companies or government bureaucracies, to relate to occasionally insensitive health care professionals to manage the needs of caring but occasionally over protective relatives.
She must be self-confident and make important family decisions without access to her most important sounding board, the man she married. She must learn to suppress her own needs for companionship and, at the same time, not lose hope that her husband’s self-esteem will return to the point where he can provide companionship again.

She must have considerable energy to work, look after the kids, prepare meals, clean the house, provide whatever physical assistance her husband needs and still find time for friends and participation in her local Brain Injury Association. She must also be wise and patient enough to identify those activities that her husband (and children) can and will do that contribute to the operation of the home. She must not become a martyr.

Each of these women had made major adjustments in their family lives and personal character. At various points in time, they confronted the obvious decision: Do stay with the marriage and make the necessary adjustments? The one activity they identified as most instrumental in their own adjustment was the support provided by their local Brain Injury Association. Support group meetings and the opportunity to meet and discuss problems with others in the same or similar circumstances was invaluable. They felt they had the most in common with other wives whose husbands were head injured, but recognized that they are under-represented in most associations.

This weekend retreat offered these families a further opportunity to gain from the wisdom and experience of others who share in their life circumstances. As researchers, we were able to gather much of the information that would have taken considerable more time to collect through home interviews. The cost of gathering this data on a weekend retreat was roughly equal to the cost of home interviews, but the benefits, in terms of the richness of understanding for the research team, were far greater. From our perspective, this initial experiment with a family retreat weekend was a resounding success. We thank local chapters and the families that participated for making this possible.

The authors of the paper include Barry Willer, Ph.D. Second authors are Marcia Liss & Miriam Arrigali.
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