

Spouses of Persons Who Are Brain Injured: Overlooked Victims

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Abstract

The cognitive and behavioral sequellae to brain injury pose significant coping problems for the victim's spouse. The resulting (and often permanent) changes in the marital relationship create difficult, painful decisions for the healthy spouse. Intervention from a knowledgeable, caring counseling professional can help in the resolution of this complex problem. Mutual support groups have provided unique benefits to spouses in various parts of the country.

Joan and her family (husband Rick and son Jamie) were enjoying their life. She and Rick were in their mid 20s and Jamie had just turned three. They enjoyed their jobs, had recently achieved financial stability, and looked forward to a promising future. Last May, Rick was involved in an auto accident and sustained a severe head injury. From that moment, Joan's life was never the same. She has been living with the unique dilemma of

being married to someone with a relatively new disability -- brain injury. Brain injury can be caused by a number of physical problems: trauma, anoxia, ruptured aneurysm, or brain abscess. Only in recent years, have many patients been surviving the initial medical event which produces residual brain damage. Therefore, the health care system is struggling with a new disability.

Although the content of this article is pertinent to all forms of brain injury, special attention will be given to the situation resulting from traumatic head injury. An estimated 700,000 Americans are victims of head injury each year (Virginia Head Injury Foundation, no date). Of all age groups, 15 to 24 year olds had the highest rate of head injuries. Males had a rate of head injuries more than twice that of females... The chief cause of head injuries was motor vehicle accidents (Anderson, Miller, & Kalsbeek, 1983, p.475). When an individual is brain injured, some characteristic changes occur which seem to persist beyond the recovery period.

Mauss-Clum and Ryan (1981) indicated that these changes include:
Decreased Memory

Dependency
 Depression
 Impatience
 Decreased ambition/initiative
 Irritability
 Temper Outbursts
 Decreased Ability to Learn from Experience
 Decreased Self-Control
 Sexual Disinterest/Preoccupation
 Self-Centered Behavior
 Inappropriate Public Behavior
 Inflexibility

The likelihood that significant cognitive and behavioral change will not be accompanied by visible physical disability creates a unique problem -- the injured individual may appear completely normal. Friends, acquaintances, or family members may innocently complicate the situation by expecting too much from the brain injured individual.

Because head injury usually affects young males, involved family members tend to be parents. While their numbers are smaller, spouses of brain injured individuals (usually female) represent a significant group of victims who are often overlooked.

Impact of Brain Injury on the Spouse

Typically when one member of a family system is affected by a disabling illness or injury, other members of the family system experience significant changes also. Particularly dramatic changes take place when a spouse is brain injured. Roles within the family are quickly, and often permanently, changed. The injured partner is normally unable to carry out his or her responsibilities

and duties. The uninjured spouse frequently must assume singular responsibility for a variety of tasks: household management, parenting, maintenance of an income, visiting and/or caring for the injured spouse, decision making, and dealing with the health care and social service system.

These additional demands on the healthy spouse are compounded by the unique care needs posed by the injured partner. When brain injury is accompanied by a physical disability, the partner may be called upon to render physical care or arrange for care to be provided.

The cognitive and behavioural changes that normally result from brain injury most often create a need for supervision of the injured individual; despite the necessity of this supervision for safety, it is often resented by the injured spouse who has little awareness of the changes in his or her cognition and behavior (Thompson, 1974). Additionally, the prodding and encouragement that are necessary to deal with the decreased ambition and initiative are emotionally and physically fatiguing for the healthy spouse.

These dramatic changes in the family system take place at a time when the healthy spouse is experiencing the absence of a partner. Gone is the special warmth and affection that the spouse could count on during difficult times.

Colman (1984) noted that "... the patient's condition precludes any awareness or expression of gratitude for the care received or concern for the caregiver's emotional or physical

state". There is an interruption in the sexual relationship between partners. Shared decision making is no longer possible.

As a member of the Colorado Spouses Support Group in Denver described it: "I'm a married widow. It's like caring for a child. I used to have a husband and seven children, now I have eight children." (Anonymous, Personal Communication, February, 1985). In their research, Mauss-Clum and Ryan (1981) reported that "almost half of the wives identified with the statement 'I'm married but don't really have a husband'".

The Spouse's Reaction

The reaction of family members to brain injury can be compared to the mourning process which accompanies most significant losses. However, this process is uniquely complicated for the spouse of a brain injured individual.

Since the onset of the problem is normally sudden, the initial reaction is shock and disbelief; during the early stages of the crisis there is customarily a mobilisation of support from family and friends. The injured individual is often comatose and being treated in a critical care unit. When the medical crisis is over and the coma begins to resolve, the family must deal with the unique behaviour associated with early brain injury recovery (i.e., confusion and agitation).

These effects are well described in the Rancho Los Amigos Levels of Cognitive Functioning (Malkmus,

Booth & Kodimer, 1980). This dramatic behaviour change in the injured individual diminishes the family's belief that their loved one will simply "wake up" from the coma and be the same again.

Despite the unusual, and often embarrassing, post-coma behaviour, the family observes rapid changes during this segment of recovery. The notable progress at this stage, particularly when compared to coma, recreates the family's belief that the injured individual will recover fully. The family normally maintains this belief in 100% recovery throughout the inpatient hospitalisation. Discharge from the hospital often signals that the crisis is over and the support of family and friends gradually fades.

After release, outpatient treatment customarily takes place for an extended period of time. Much later, when outpatient treatment is discontinued, the family begins to realise that some of the deficits created by the injury may be permanent. This awareness tends to precipitate depression among family members, a reaction that is not necessarily shared by the injured individual since, as Thompson (1974) reported, the patient often lacks awareness that any change has taken place as a result of the injury.

At this phase of the mourning process, unique problems commence for the spouse.

The changes in cognition and behaviour that are common sequelae to a brain injury create

characterological alteration in the injured spouse (Lezak, 1978; Thompson, 1974).

As another spouse described this situation: "it's like living with a stranger" (Anonymous, Personal communication, February, 1985). The healthy spouse not only mourns the specific losses that his or her partner has experienced, but also her essential loss of a partner. Unlike a widow or widower who has visibly lost a husband or wife, the spouse with a brain injured individual cannot openly mourn the "death" of the person. Lezak (1981) indicates that:

Religious scruples, social pressures, guilt, feelings of indebtedness and gratitude are among the attitudes and expectations that can obstruct the very delicate and socially unacceptable task of mourning and emotionally burying a living person.

The healthy spouse's grieving may be misunderstood by family and friends. The spouse of a head injured individual may also experience a feeling of entrapment. If he or she contemplates leaving the marriage he or she may be faced with the reality that there is no one to care for the partner. The guilt feelings that often accompany the consideration of leaving the spouse are, at times, enhanced by in-laws who expect persistence "for better or worse, in sickness and in health."

During this difficult time, the spouse may have real problems finding friends or professionals who truly understand the dilemma.

The conclusion of this mourning process may take two forms: mobilisation to leave the marriage or remaining in the marriage and assuming the role of caretaker. Many young spouses opt to terminate the marriage so that they can re-establish a meaningful life for themselves and their children. Other spouses complete the process of grieving their "lost" partner, but remain available as a caretaker. Lezak (1981) summarised the caretaker role by noting that:

Emotional detachment may free the caretaker from the guilt or concern about propriety that have kept her housebound or him home every evening and weekend. He or she may now be able to engage in social activities or work outside the home in realistic efforts to rebuild a meaningful life for at least some of the time. Other family members may not experience a change in what they do as much as an emotional reorientation that can give them some peace and emotional liberation. These are the caretakers who come to view their role as just that and the previous relationship to the patient dissolves.... One elderly wife, for example, thinks of herself as a hired housekeeper with no emotional ties to the patient.

In this way, she can continue to care for a very self-absorbed, irascible husband with minimal emotional pain or involvement.

The role of caretaker is not without problems. Brain injured individuals who remember an equal partnership in their marriage pre-morbidly often show resentment when being "parented". If spouses succeed in

developing some fulfilment or achievement, their injured partners, who may be unable to achieve success, often react with anger.

Thus, in addition to the customary process of grieving the losses that occur with the tragedy of brain injury, most spouses must also deal with the loss (without death) of the person they married. This complicated mourning process is often compounded by the demanding task of caring for the injured individual.

Intervention strategies

Families experiencing the tragedy of brain injury will have different needs for intervention during the various stages of dealing with the disability. The one factor that remains constant during this coping process is the necessity for professional services provided by someone knowledgeable about the aftermath of brain injury.

During the initial crisis and hospitalisation, the counselling professional must understand and deal with the family's denial. As Lezak (1981) indicated:

Initially, counselling can do little more than serve to lay down the groundwork for future counselling. While the patient is still in a rehabilitation program or has just come home, most families are unable to accept a realistically dismal prognosis.

As families begin to gain awareness that the injury has changed their lives, the counsellor can help them start to explore the dimensions of the

problem. Lezak (1981) suggested that:

The counsellor who can be gently and discretely honest ... about the patient's condition can help family members notice how the patient has changed and thus help them to come to terms with this sooner. Perhaps the most useful thing the clinician counselling the family of a recently brain injured person can do is to earn their trust and let them know that he or she will be available to them in the future.

As the full reality of their situation becomes apparent, the family may be ready for more intensive intervention. This stage in the coping process unfortunately occurs when many families have lost touch with all professionals. Again, the availability of a counselling professional knowledgeable about brain injury is very important to the success of intervention.

The focus of services to the family usually encompasses:

- Recognition of the losses,
- Acceptance of the need to mourn,
- resolution of guilt, and
- An objective exploration of options.

At this point spouses are particularly able to benefit from involvement with other spouses in a group setting.

The therapeutic milieu provided by a group of other spouses experiencing this unique dilemma can be very constructive. Such a group was developed in Denver, Colorado under the auspices of the Colorado Head Injury Foundation in the summer of 1983. Spouses of brain injured

individuals meet monthly to educate themselves and discuss common problems.

Approximately three years ago, an interstate support group for wives of head injured men ("Connect") was founded by Lisa Barker in Richmond, Virginia.

Because the local head injury support groups were not able to address the unique needs of spouses, she established a network through the National Head Injury Foundation which offers mutual support by correspondence or telephone. Lisa remains the focal point of the active group that bridges the miles between spouses needing help.

In 1977, a group called "Woman Who Care" was established in Marin County, California to meet the needs of elderly care giving wives, many of whom had husbands with cognitive and behavioural problems.

The group began as a mutual support group but soon expanded to an advocacy group which was successful in establishing a "Wives Respite Project" (Crossman, London & Barry, 1981).

In discussing support groups, Colman (1984) indicated that:

..... support groups play a very significant role in helping care-giving wives. The isolation expressed from loss of friends and family disappears when these woman come together.

They learn that it is all right to cry, to feel angry and resentful, and to resolve their feelings of guilt when

they wish that their husbands would die.

Although these programs are essentially self-help groups, they are often facilitated by professionals. The availability of such self-help groups is, however, limited by the small number (compared to parents) of spouses affected by the problem.

Thus, intervention must proceed at a pace with which the family is comfortable. It must be conducted by a caring professional who has knowledge of the unique problems associated with brain injury. And intervention can frequently take the form of a self-help group where victims help other victims.

In addition to intervention, Lisa Barker, who founded "Connect", has some suggestions for the basic survival of spouses. Professionals can encourage spouses to:

- Read as much available literature as possible in order to fully understand the problems which need to be faced;
- Read or locate resources to develop self-esteem;
- Participate in a vigorous exercise program;
- Make arrangements for true respite (Lisa Barker, Personal communication, April 15, 1985).

The classic cognitive and behavioural deficits associated with brain injury pose significant problems for affected individuals and their families, particularly spouses.

Helping families cope with this disability means being available to

them for a long time. Spouses in particular, need to have someone intervene who understands their unique dilemma. Individual, family and group approaches to intervention can all be helpful.

When speaking of disability in general, Dell Orto (1984) summed up this situation articulately:

When discussing the differential impact of disability we must be aware that the resources, problems, hopes and dreams of people are a different

as snowflakes. While the element of individuality is the key to emotional survival, it must be fuelled by the commonality which all challenged people and their families share.

This commonality is the active ingredient which can enable people to negotiate the perils of the physical and emotional rehabilitation process by recognising they are not alone and seeing that it can be done.