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UNIVERSITY OF ALBERTA

WIVES' ADAPTATION TO HUSBANDS WITH BRAIN INJURIES

BY

PENNY FORD

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY.

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

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Dr. Peter Calder

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Dr. George Fitzsimmons

Dr. Dick Sobsey

Dr. Clarence Preitz

for Willer

Dr. Barry Willer

Date: February 19, 1993

DEDICATION

To women whose husbands have brain injuries.

ABSTRACT

The purpose of this research was to investigate the process of adaptation of women following their husbands' brain injuries. Research in the area of spousal adaptation following brain injury is important in terms of the psychosocial health of the wives, the maintenance of functional family units, and the rehabilitation of individuals with brain injuries.

Data collection involved the administration of a brief telephone interview and a package of self-report measures to 62 women. The telephone interview included the collection of demographic and injury related information and the administration of two open-ended questions, the Portland Adaptability Inventory (Lezak, 1987), and the Subjective Burden Scale (McKinlay, Brooks, Bond, Martingage, & Marshall, 1981). The mail-out self-report measures included the Dyadic Adjustment Scale (Spanier, 1976), the Social Support Inventory (McCubbin, Patterson, Rossman, & Cooke, 1982), the Family Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, & Larsen, 1981), and the Family Member Well-being Index (McCubbin & Patterson, 1982).

The analyses included qualitative analyses of the two open-ended questions, descriptive statistics on the telephone interview and self-report measures data, comparisons of the study data with normative data, and correlations among all of the variables. Five themes emerged in relation to the effects of their husbands' brain injuries on the women and four themes emerged in relation to how the women dealt with these effects. The correlational analyses indicated that the husbands' levels of psychosocial functioning and the wives' levels of subjective burden, dyadic adjustment, and coping were associated with their levels of well-being while their levels of social support were not associated with their levels of well-being.

It was concluded that women experience difficulties in adapting to the changes in their lives as a result of their husbands' brain injuries. It was suggested that these women require information and support early in the rehabilitation process and over the long-term. It was suggsted that programs be developed in order to assist in the adaptation process. It was also suggested that further investigation, using both quantitative and qualitative methodologies, be undertaken in order to clarify the variables involved in the adapting to the effects of brain injuries.

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A final thank you is due those women who participated in this research. I am grateful for their time and efforts and sincerely hope that the findings of this study will be of benefit to them.

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CHAPTER 1 - INTRODUCTION

The purpose of this study was to investigate the process of adaptation of women following their husbands' brain injuries. The investigation of spousal adaptation following brain injury is important both in clinical counselling situations and in the development of group support programs.

As a result of their potentially devastating physical, psychological, and social consequences, brain injuries are one of the most critical problems facing the health care system today. The problems of individuals with brain injuries "are enormous and the socioeconomic impact on our society is staggering" (Rimel, Jane, & Bond, 1990, p. 8). Even though brain injuries are recognized as a major international health problem, the epidemiology is not well described because of problems in defining brain injuries and in identifying individuals who have sustained brain injuries.

In Canada, the most commonly quoted annual incidence figure for brain injuries requiring hospitalization is 200 cases per 100,000 population (Parkinson, Stephenson, & Phillips, 1985). As paramedic response time decreases and emergency medical technology improves, the number of individuals with brain injuries who survive will increase, with concomitant increases in the number of individuals with disabilities.

Definition and Classification of Brain Injury

Brain injuries can be broadly classified as either traumatic brain injuries or "other types" of brain injuries that can result from a wide variety of causes including aneurysms, arteriovenous malformations, tumors, blood clots, and surgical interventions.

Traumatic brain injuries are defined as damage to living brain tissue that is caused by an external mechanical force. Traumatic brain injuries are most often caused by motor vehicle accidents, falls (domestic), industrial-related accidents, recreation-related accidents, motorcycle-related accidents, and assaults. There are primary and secondary processes by which brain damage occurs, the primary forces being compression, tension, and shearing (twisting). These forces produce both diffuse and localized damage. When a head strikes the windshield of a car, for example, the brain (which is floating in cerebrospinal fluid) smashes into the skull. This compression at the site of impact tears and bruises nerve fibres and is termed a contusion. Certain areas of the skull, most notably the base of the frontal and temporal lobes, have bony ridges that enhance the likelihood of contusion at these sites. In addition to primary mechanisms, secondary mechanisms commonly occur resulting in further damage. Secondary brain damage is the result of subsequent pathologic processes including brain swelling, intracranial hematoma, and the effects on the brain of extracranial events such as blood loss, arterial hypotension, and pulmonary complications.

Brain injuries are often characterized by a period of altered consciousness (amnesia or coma) that can be as brief as a few minutes or long as many years. The resulting tissue damage can impair an individual's physical, mental, or psychosocial abilities (Vogenthaler, 1987). Individuals who have cognitive dysfunction following brain injuries, whether it is secondary to traumatic brain injuries, strokes, or surgical interventions, have many of the same characteristics and problems. The most common consequences of brain injuries can include the following: short and long-term memory loss, decreased learning ability and diminished ability to think and reason, decreased ability to concentrate, inappropriate behavior, lack of initiative and motivation, fluctuating levels of mood and emotion, difficulty in communicating, and physical disabilities (Dring, 1989).

In addition to the above mentioned difficulties, Dring (1989) suggests that cognitive impairment usually involves an altered ability to process information, which in turn disrupts the ability to respond to stimuli and carry out activities of daily life. As well, individuals may lose their capacity for interpersonal sensitivity. These difficulties can have dramatic ramifications for spouses of individuals who have brain injuries.

The severity of brain injuries is most commonly determined by the depth of coma as measured by the Glasgow Coma Scale (GCS) and the period of unconsciousness or posttraumatic amnesia (PTA). The GCS is a 13 point scale, ranging from 3 through 15, divided into three categories of neurological responsiveness: eye opening, verbal responses, and motor responses (Teasdale & Jennett, 1974). Brain injuries are generally classified as mild, moderate, or severe. The term "mild" has typically been used to define brain injuries in which the period of unconsciousness is relatively short (fewer than 20 minutes), there is no known structural damage to the skull or brain, and GCS scores range from 13 to 15. Moderate brain injuries are usually defined as a GCS score of 9 to 12 and a loss of consciousness of between 20 minutes and 24 hours. Severe brain injuries are most often defined as a GCS score of 3 to 8 and a loss of consciousness of greater than 24 hours. The focus of research in recent years has shifted away from the severe end of the brain injury spectrum with the realization that approximately 90% of all brain injuries are classified as mild or moderate in severity (Gouvier, 1986).

The Effects of Brain Injuries on Wives

In recent years the family has become a focal point in the rehabilitation process for individuals with brain injuries. It has been suggested that the family's adaptation to the injury and its' sequelae has a significant impact on the rehabilitation of the member with the brain injury and may account for a considerable part of the difference in final outcomes that has been observed between individuals with similar degrees of brain injury (Bond & Brooks, 1976). Frank, Haut, Smick, Haut, and Chaney (1990) suggest that the ability of the family to adapt to stressors is especially significant given the importance of the family to the individual with the brain injury. Mauss-Clum and Ryan (1981) suggest that patients with strong family support progress further than those without family involvement. Rosenthal and Young (1988) argue that rehabilitation professionals' failure to understand family dynamics following a brain injury and to provide appropriate interventions will likely limit the potential success of any rehabilitation program. Thomsen (1974) and Livingston, Brooks, and Bond (1985) point out the need for comprehensive long-term treatment and support for both the individual with the brain injury and family members. Dring (1989) suggests that the family plays an important role in the rehabilitation process by either encouraging rehabilitation or retarding rehabilitation and causing severe psychological and economic strain on the family. Dring (1989) further suggests that "very few caregivers are prepared to meet the challenge of caring for their loved ones at home. They lack nursing skills, knowledge of their own rights, knowledge of available help and how to obtain it, coping skills, and support systems" (p. 42).

Several researchers have found that continuing problems for the individual with the brain injury may cause serious family distress (Brooks & McKinlay, 1983; Lezak, 1978; McKinlay et al., 1981; Rosenbaum & Najenson, 1976; Thomsen, 1987). When one member of a family system experiences a disabling injury, other family members are inevitably affected. The impact will depend on several factors including the composition of the family group, its' place in society, the role formerly played by the injured person, and the ability of each member of the family to cope with the stress that develops (Bond, 1983).

The impact can be particularly traumatic for a spouse. Lezak (1988) suggests that it is the person who assumes the role of primary caregiver who carries the greatest part of the burden, while the severity of stress on other family members most typically varies according to their capacity for independence from the injured individual and the primary caregiver. Zeigler (1987) describes the spouses of individuals who have sustained brain injuries as "overlooked victims".

Peters, Stambrook, Moore, and Esses (1990) suggest that brain injury rehabilitation teams must be more sensitive to the needs of the injured individuals' spouses and should begin to allocate more resources for the involvement of spouses in rehabilitation programs. Furthermore, their findings emphasize that the need for spousal intervention exists on a relatively long-term basis and does not end after hospital discharge of the individual.

Several studies in the literature have investigated variables related to caregiving by the relative of a person experiencing dementia (Aronson, Levin, & Lipkowitz, 1984; Cantor, 1983; Dring, 1989; George & Gwyther, 1986; Gilhooly, 1984; Gilleard, 1984; Haley, Levine, Brown, & Batolucci, 1987; Quayhagen & Quayhagen, 1988; Scott, Roberto, & Hutton, 1986; Sistler, 1989; Springer & Brubaker, 1984; Wilson, 1990). No studies in the literature, however, have attempted to investigate, in any systematic way, the variables involved in the adaptation process of the wives of men with brain injuries. This study investigated the relationships among six variables related to the adaptation of wives of men who had sustained brain injuries. These variables included the levels of psychosocial functioning of the husbands as reported by their wives and the wives' levels of subjective burden, dyadic adjustment, social support, coping, and well-being.

Plan of the Dissertation

Chapter 2 begins with a description of the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin and McCubbin (1991). The literature relevant to the variables, related to particular dimensions of this model, that were chosen for investigation are then reviewed. These variables included the levels of psychosocial functioning of the husbands and the wives' levels of subjective burden, dyadic adjustment, social support, coping, and well-being. The purpose and rationale for the study are also described. The final section of this chapter outlines the hypotheses and research questions addressed by the study.

Chapter 3 outlines the methods and criteria for the selection of women participating in the study. The procedure for data collection and the self-report measures employed are described. In addition, the methods of data analysis are presented.

In chapter 4 the results of the investigation are presented. The sample of women participating in the study are described. The results of the qualitative analyses of the two open-ended questions from the telephone interview are described. Correlations between the scores on the six self-report measures and between the self-report measures and a number of demographic variables are examined. Summary statistics are presented for each of the self-report measures and where possible the results are compared with existing normative data. In addition, the findings regarding some additional analyses which were undertaken are presented.

Chapter 5 is a general discussion of the findings. Results are summarized and placed within the context of the literature presented.

Chapter 6 includes an overall summary of the research. In addition, the limitations of the study are described, implications for practice are discussed, and some directions for future research are outlined.

CHAPTER 2 - REVIEW OF THE LITERATURE

Introduction

The follow[illegible]apter begins with a description of the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin and McCubbin (1991). The literature relevant to the specific variables in this model that were chosen for investigation are then reviewed. These variables included the levels of psychosocial functioning of the men with brain injuries and their wives' levels of subjective burden, dyadic adjustment, social support, coping, and well-being. These variables were chosen as a result of their particular relevance to the adaptation process of women following their husbands' brain injuries and the potential of these variables for clinical intervention.

Resiliency Model of Family Stress, Adjusment, and Adaptation

Hill (1949, 1958) developed the first conceptual foundations for research to examine the variability in family pre-crisis adjustment response with the ABCX family crisis model. Since 1970, investigators have carried on family stress research in an effort to clarify and provide empirical support for these original conceptualizations (Burr, 1973; McCubbin, 1979). McCubbin and Patterson (1981, 1983), built on Hill's original model and developed the Double ABCX Model of Family Adjustment and Adaptation. This model focused upon the stressor, the family's resistance resources, and the family's appraisal of the stressor. McCubbin and McCubbin (1987) introduced new developments in the major components of the Double ABCX Model of Family Adjustment and Adaptation. Specifically, they introduced family types and expanded upon the family strengths components of the theoretical framework, with an emphasis on the family appraisal component of family stress theory. This version of the family stress model was called the T-Double ABCX Model of Family Adjustment and Adaptation. McCubbin and McCubbin (1991) renamed this model the Resiliency Model of Family Stress, Adjustment, and Adaptation.

This model attempts to describe families at two stages in their response to normative family transitions and major life changes and illness. The first phase is the Adjustment phase and the second is the Adaptation phase. Since not all changes or transitions create family crises or call for major shifts in the family's rules or patterns of behavior, the Adjustment phase of the model focuses upon those family types, strengths, and capabilities that explain why some families are better able to adjust to minor changes that do not require major alterations in family functioning. Other transitions, such as the death or chronic illness of a family member, call for a major shift in the way the family typically operates, and, therefore, a crisis emerges. A state of family crisis is characterized by "the family's situational inability to restore stability, by its' cyclical trial and error struggle to reduce tension complemented by efforts to make changes in family structure and patterns of interaction which also contribute to the family's instability" (McCubbin & McCubbin, 1991, p. 14). The second phase of the model, the Adaptation phase, attempts to guide research concerning how families use or develop their types, strengths, and capabilities to manage and adapt to a major change. This phase predicts the degree of disruption in functioning a family is likely to experience in the face of a particular stressor event and the family's capacity to adapt and to achieve a new balance in functioning after a major crisis has occurred.

It is assumed that a brain injury sustained by a husband that results in chronic physical, emotional, and cognitive changes will create a crisis in the family. This will be true regardless of the previous level of family adjustment, although it is reasonable to expect that families who are better able to negotiate minor changes are also likely to be better able to deal with a major change. Hence, it is the Adaptation phase of the Resiliency Model of Family Stress, Adjustment, and Adaptation that provides a framework for the current research. The Adaptation phase of the model has the potential to help rehabilitation professionals understand certain variables involved in the adaptation process of women following the crises of their husbands having sustained brain injuries. In order to maintain clarity and theoretical continuity, however, the Adjustment phase is outlined briefly in the following sections prior to a more detailed review of the Adaptation phase of the model.

The Adjustment Phase

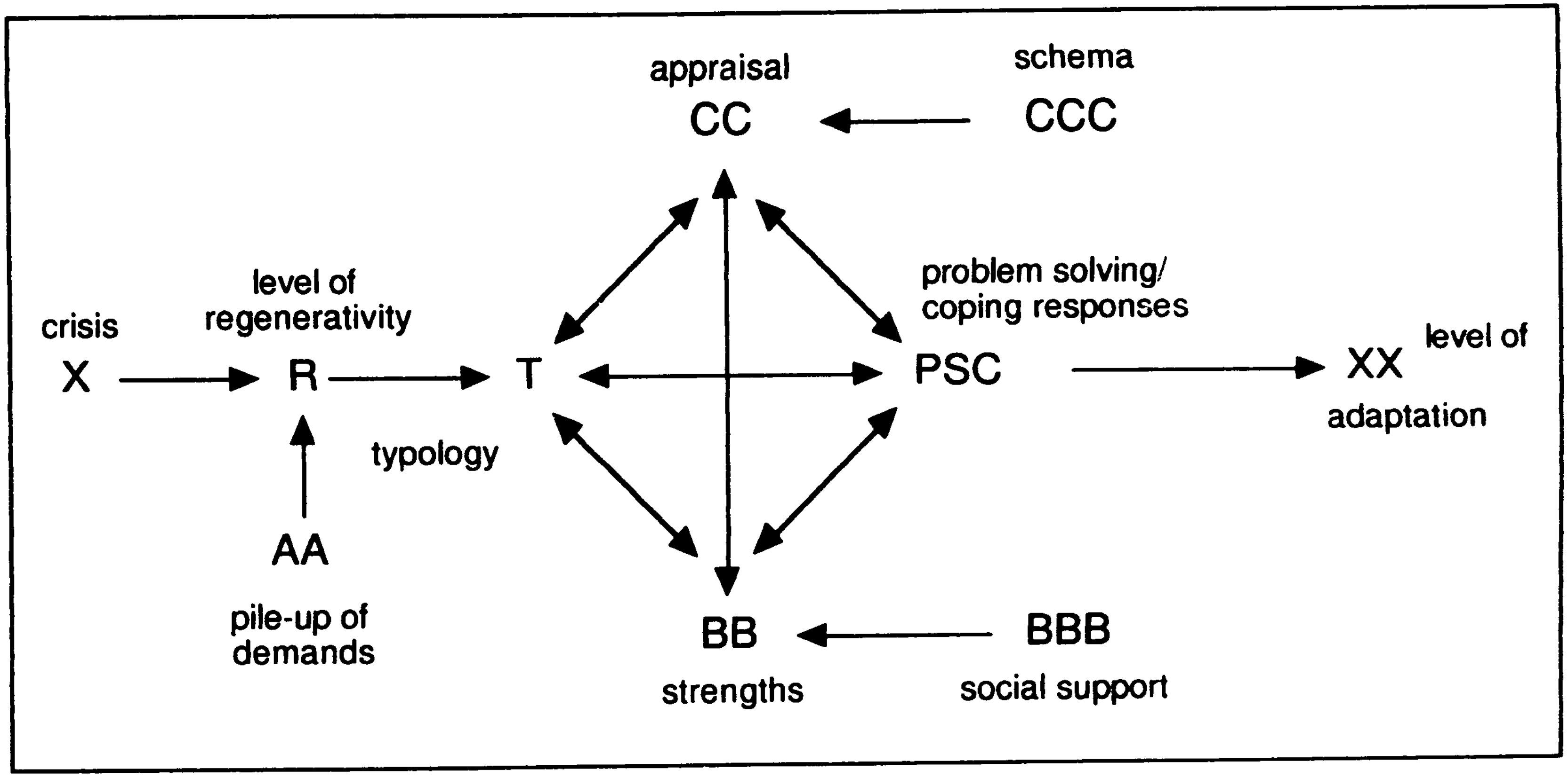
The first stage of the model is the Adjustment phase, which is concerned with those family types, strengths, and capabilities that explain why some families are better able to adjust to relatively minor changes, transitions, or demands that do not require major alterations in family functioning. The following are the components of the Adjustment phase in the Resiliency Model: A, the stressor event or transition and its' level of severity; V, the family's vulnerability determined, in part, by the concurrent pile-up of demands (stressors, transitions, and strains) and by the family's life cycle stage; T, the family's typology (regenerative, resilient, rhythmic, balanced, or traditionalistic); B, the family's resistance resources; C, the appraisal the family makes of the event; and PSC, the family's problem solving and coping responses to the family situation, including the demands created by the stressor as well as the stressor event/transition itself. Each of these components will interact to determine X, which is either the level of family adjustment or the family's transition into a crisis situation.

The Adaptation Phase

McCubbin and McCubbin (1991) suggest that the assessment of family adaptation requires a dynamic model that focuses on family efforts over time to recover from a crisis. The Resiliency Model, which emerged from studies of war-induced family crises (McCubbin, Boss, Wilson, & Lester, 1980; McCubbin & Patterson, 1981, 1983), added post-crisis variables to Hill's original ABCX model in an effort to describe (a) the additional life stressors and changes which may influence the family's ability to adapt, (b) the critical psychological, family, and social factors families can call upon and use to adapt, (c) the processes families engage in to adapt, and (d) the outcome of these family efforts (McCubbin & McCubbin, 1991).

A diagram of the Adaptation phase is provided in Figure 1. The level of family adaptation in response to a crisis situation is determined by the following: AA, the pile-up of demands on the family system created by the crisis situation, life cycle changes, and unresolved strains; R, the family's level of regenerativity, which is determined in part by the concurrent pile-up of demands (stressors, transitions, and strains); T, the family's typology (resilient, rhythmic, balanced, regenerative, or traditionalistic); BB, the family's strengths (the family's adaptive strengths, capabilities, and resources); BBB, the support from friends and the community (social support); CC, the family's appraisal of the situation (the meaning the family attaches to the total

Figure 1. Outline of Adaptation phase of Resiliency Model



Note. From *Family Assessment Inventories for Research and Practice* (p. 15) by H.I. McCubbin and A.I. Thompson, 1991, Madison, WI: University of Wisconsin-Madison.

situation); CCC, the family's Schema (world view and sense of coherence which shapes the family's situational appraisal and meaning); and, PSC, the family's problem solving and coping responses. Each of the variables of the Adaptation phase of the Resiliency Model is discussed briefly in the following sections.

Factors Related to the Wives' Adaptation to their Husbands' Brain Injuries

Stress

McCubbin and McCubbin (1991) suggest that because family crises evolve and are resolved over a period of time, families seldom deal with only a single stressor. Rather, families experience what they describe as a "pile-up of demands", particularly from chronic stressors such as caring for a disabled family member or a major role change for one member. This would be the case in a family in which the husband sustained a brain injury and the wife had to assume some or all of the responsibilities of his role. McCubbin and McCubbin (1991) acknowledge that the demands in and on the family are constantly changing including the ever changing developmental stages of family members and changes in society. McCubbin and McCubbin (1991) identify five broad types of stressors and strains that contribute to a "pile-up" in the family system (a) the initial stressor and its' hardships; (b) normative transitions; (c) prior strains; (d) the consequences of family efforts to cope; and (e) ambiguity, both intra-family and social. In this study the initial stressor was considered to be the husband's brain injury. The "stress" experienced by the woman in relation to her husband's brain injury was investigated by the use of two measures. The first measure was the woman's assessment of the level of the psychosocial functioning of her husband. This was considered to be a measure of a "hardship" engendered by the initial stressor. The second measure was the woman's perception of the "level of burden" she experienced in relation to the effects of her husband's brain injury. The subjective burden experienced by the woman may include aspects of the "pile-up" as described by McCubbin and McCubbin (1991) such as normative transitions, prior strains, consequences of family efforts to cope, and intra-family and social ambiguity. McCubbin and McCubbin (1991) describe normative transitions as including the normal growth and development of family members and of extended family and family life cycle changes. In terms of prior strains, Pearlin and Schooler (1978) suggest that families experience ongoing strains that may be the result of unresolved hardships from earlier stressors or transitions or the result of present roles. When a new stressor is experienced by the family these prior strains are exacerbated and contribute to the stress of the crisis. In terms of efforts to cope, McCubbin and McCubbin (1991) suggest that additional stressors may emerge from certain behaviors that family members use in order to cope with the crisis. For example, returning to work in order to provide financial support for the family may cause additional stress for the woman. In terms of intra-family and social ambiguity McCubbin and McCubbin (1991) suggest that a certain amount of ambiguity is inherent in every crisis, since change and the demand for adaptation create uncertainty about the future. Internally, the family may experience ambiguity about its' structure and about family roles, rules, responsibilities, and durability. In addition, families may experience social ambiguity in those situations in which social prescriptions for crisis resolution and family adaptation are unclear or absent.

Psychosocial functioning of the husbands.

A review of the literature related to the stress experienced by close relatives of individuals with brain injuries indicates that the level of stress is often assumed to be related to the severity of the brain injury. Tate, Lulham, Broe, Strettles, and Pfaff (1989) suggest, however, that a feature of recovery from severe degrees of blunt brain injury is that the ultimate level of outcome varies markedly among individuals, ranging from severe disability to good recovery. Furthermore, numerous researchers have demonstrated that mild and moderate levels of brain injuries can have as deleterious a consequence as severe injuries for injured individuals and their family members (Alves, 1989; Binder, 1986; O'Shaughnessy, Fowler, & Reid, 1984; Rimel, Giordani, Barth, Boll, & Jane, 1981; Stuss, Ely, Hugenholtz, LaRochelle, Poirier, & Bell, 1985). In addition Gilleard (1984) suggests that caring for a mentally impaired person creates a greater strain than caring for a physically ill person.

Individuals with brain injuries can exhibit cognitive and behavioral disabilities many years post-injury and, according to recent research, such disabilities are the greatest obstacles to employment and community reintegration (Ben-Yishay & Diller, 1981; Bond, 1979; Oddy & Humphrey, 1980). Liss and Willer (1990) suggest that typical problems of individuals who have sustained severe traumatic brain injuries include difficulties with attention and concentration, planning, impulsivity, communication, memory and information processing, and judgement and perception. Willer, Liss, and Arrigali (1989) examined the problems and coping strategies of individuals with traumatic brain injuries and their spouses. Able-bodied wives reported that the biggest problems were the personality changes of their husbands, their husbands' lack of insight into their disabilities, and the role performance changes in companionship, child rearing, and financial support. Willer, Allen, Liss, and Zicht (1991) found that wives of individuals with brain injuries identified changes in the personalities of their husbands as their greatest problem, followed by cognitive difficulties encountered by their husbands, their husbands' lack of insight and acceptance of their disabilities, the reduction in income, and the loss of emotional support and companionship they had previously received from their husbands. These women described feeling that they had lost their best friend. Women with children expressed concerns regarding the effects on their children of having fathers with brain injuries.

Several investigators in the area of brain injuries suggest that the most consistent and, on a long-term basis, the most disabling consequences of brain injuries are the impairments in what can be termed "psychosocial functioning" (Hendryx, 1989; Jennett, Snoek, Bond, & Brooks, 1981; Mauss-Clum & Ryan, 1981; McKinlay et al., 1981; Oddy, Humphrey, & Uttley, 1978a, 1978b; Weddell, Oddy, & Jenkins, 1980). Psychosocial functioning encompasses behavioral and emotional sequelae (irritability, self-centeredness, lack of initiative, mood swings, impulsivity, restlessness, anxiety, and depression) as well as cognitive difficulties (poor concentration and forgetfulness). Several authors have documented the disastrous social consequences of such sequelae including marital breakdown, unemployment, and social isolation (Oddy, Coughlan, Tyerman, & Jenkins, 1985; Oddy et al., 1978a, 1978b; Thomsen, 1984). It has been suggested that it is these psychosocial deficits which have the greatest relevance in terms of the stress experienced by the partner.

Thomsen (1987) suggests that by 1 year post-injury the injured individual's emotional and behavioral disturbances as reported by the closest relative are the best predictors of stress in the relative. In response to these findings this study investigated the relationship between the wives' levels of adaptation and their levels of stress as measured by their assessment of their husbands' current levels of psychosocial functioning (at the time of the investigation).

Subjective burden experienced by the wives.

Researchers have begun to examine the main features of psychosocial burden as perceived by the relatives of individuals with brain injuries (Brooks & Aughton, 1979; McKinlay et al., 1981). Psychosocial burden upon a family may be considered in two quite different ways: (a) objective burden type 1, which includes changes in family routine, family health, housing conditions, financial status, and social and leisure activities and objective burden type 2, which includes post-traumatic symptoms and changes in the behavior and personality of the individual with the brain injury; and (b) subjective burden which is the stress felt by the person caring for the injured individual resulting from the presence of objective burden. Objective burden type 1 reflects changes forced upon a family by the presence of the injured individual, and objective burden type 2 burden reflects changes and symptoms in the injured individual which have resulted directly from the injury. These may be referred to as "objective" burdens that may be observed clearly and reliably by an independent observer. In addition, there is the "subjective" burden or the stress felt by family members caring for the injured individual. McKinlay et al. (1981) suggest that an estimation of this kind of burden is less easy. They assessed "subjective" burden by asking relatives of individuals with brain injuries to rate their strain or distress using a 7-point rating scale.

Brooks and McKinlay (1983) found that the association between the injured individuals' personality changes and the relatives' burden increases over time. Over a 1 year period the relatives showed a decreasing ability to accept, and cope with, negative changes in the injured individuals' behaviors. They found that the relationship between subjective burden in a close relative and general emotional and behavioral changes in the individual with the brain injury is very strong, whereas the relationship between burden and physical changes in the individual with the brain injury is weak.

Livingston, Brooks, and Bond (1985) found that high self-rating of burden continued in the relatives of severely injured individuals throughout the year following injury. They found that distress in the relatives seemed to be associated more with day to day symptomatic complaints than with the initial severity of injury.

Brooks, Campsie, Symington, Beattie, and McKinlay (1986) interviewed close relatives of individuals with severe brain injuries 5 years post-injury. With the exception of a slight increase in aggressive behavior, the injured individuals' problems did not change noticeably. However, caregivers reported significantly greater levels of stress when compared to 1 year post-injury. This may indicate that factors other than the disabled individuals' symptoms account for the caregivers' perceived burden. Brooks, Campsie, Symington, Beattie, and McKinlay (1987) followed the families of individuals with brain injuries 7 years after the injury and found that the deficits following brain injuries often persist for years with consequent burden on relatives. The researchers suggest that with the passage of time family members may develop increasing intolerance for the individual's limitations. It is also possible that family members eventually become exhausted by the demands imposed upon them.

This study used the Subjective Burden Scale developed by McKinlay et al. (1981) in order to assess womens' perceptions of the subjective burden engendered by the effects of their husbands' brain injuries.

Resources

McCubbin and McCubbin (1991) identify as separate variables in their model several different aspects of a family's resources. They emphasize two major sets of capabilities (a) resources and strengths, which are what the family has and (b) coping behaviors and strategies, which are what the family does as individual members in the family unit and what the family does collectively as a family unit. Furthermore, McCubbin and McCubbin (1991) consider there to be three potential sources of resources (a) individual family members, (b) the family unit, and (c) the community. These researchers define an adaptive resource as a characteristic, trait, or competency of one of these three sources. The first source of resources are personal resources which include innate intelligence; knowledge and skills acquired from education, training, and experience; personality traits; physical and emotional health; a sense of mastery; and self-esteem. The second source of resources are family system resources which refer to characteristics or traits of the family system itself, that is, system qualities that make the family less vulnerable to stress and/or better able to withstand the impact of stressors and crises. One critical component of these resouces is the strength of the marital unit. This has been recognized by family therapists of various clincial approaches and has been the major motive behind the marriage enrichment movement (Lavee, McCubbin, & Olson, 1987). Other family system resources include cohesion, adaptability, family organization, and communication skills. The third source of resources are community resources which include services from the government (medical and health care), schools, churches, and employers. The two resources investigated in this study were dyadic adjustment and social support.

Dyadic adjustment.

Burke and Weir (1982) report that of all possible social contacts, both men and women select their spouse as the person they would most likely turn to for help with their problems. The increasing independence and isolation of today's nuclear family magnifies the importance of this dyadic relationship.

In terms of the injured individual, McIvor, Riklan, and Reznikoff (1984) suggest that perceived spousal support is an essential resource for positive adjustment and adaptation. Blood and Wolfe (1960) suggest that the spousal system is a resource for affection, companionship, and ego strength in times of social and psychological crisis. The reactions of caring others are very important to consider because their attitudes toward the individual with the injury may in part determine how effectively they will employ whatever remaining capacity exists (Grant & Alves, 1987). In terms of elderly wives caring for disabled husbands, Wilson (1990) reports that "in some extreme cases, the wives indicated that the stress of caregiving had caused disintegration and disruption of the marital relationship. Frequent references were made to the drastic changes that occurred in the marital bond" (p. 419).

Various studies have investigated the effects of brain injuries on the dyadic relationship. Liss and Willer (1990) reviewed the research regarding the effects of traumatic brain injuries on marital relationships. Their findings demonstrate that spouses' reactions to traumatic brain injuries include feelings of anxiety, isolation, and loss.

Jennett (1990) suggests that for individuals with brain injuries who are married, these marriages frequently break down under the stress of brain damage. Following brain injury the couple's general quality of life as well as the ability of the healthy partner to care for their injured partner are affected. The quality of one's marriage is likely to influence the psychological well-being of both partners when dealing with chronic illness or disability.

Peters et al. (1990) suggest that the marital relationships of individuals with brain injuries are vulnerable to stress, that the wives of individuals with severe brain injuries experience distress following the injuries, and that they perceive high levels of burden imposed by the injuries. In their study, the marital relationships of 55 males with severe brain injuries were assessed, based on spouses' self-reports obtained through interviews and questionnaires. Dyadic adjustment was greater when wives reported a lower level of financial strain, when they perceived their spouses as having a relatively low level of general psychopathology or maladjustment, and when the injuries were relatively mild.

One study that examined the long-term adjustment of individuals with traumatic brain injuries and their families is the 15 year follow-up study by Thomsen (1989). This study describes a discouraging outcome for married individuals affected by traumatic brain injuries. Of the 40 subjects in Thomsen's study, 9 were married at the time of injury. At the 15 year follow-up only 2 of these couples had remained together. Similarly Panting and Merry (1972) found that of 10 individuals with brain injuries who were married pre-injury, 3 separated and 3 divorced from their mates, within 7 years post-injury.

Jacobs (1989a) reports that marital separation and divorce and family discord are higher among family members of individuals with traumatic brain injuries, as compared to the general population. Jacobs (1987) found that the post-injury rate of divorce or separation among those who were married at the time of injury was higher than the national average. Changes in marital status were particularly evident after the first year post-injury, which is when many formal rehabilitation programs end. Jacobs suggests that changes in marital status may be related to the ongoing difficulties of living with the effects of brain injuries. The stress of living with the effects of brain injuries is compounded by the lack of support normally provided by one's partner.

The effects of a brain injury often include personality changes for the injured individual. Spouses frequently observe that the individual is no longer the same as the person they married (Eames & Wood, 1989). The spouse may also change in response to the increasing challenges of dealing with the effects of a brain injury (Jacobs, 1989). These new personalities may create conflict with regard to the previous expectations the spouses had for each other. The stress of these changes may lead to deterioration in the marital relationship. The person with a brain injury would now be in a dependent role (Eames & Wood, 1989). Both the injured individual and the spouse may find the sudden role changes to be major sources of stress in the marriage.

Lezak (1988) notes several effects of brain injuries on spouses. She notes that spouses live in "social limbo," because they do not have partners with whom they can participate in the many social activities that are couple-oriented, and they are not free to find new partners. It is difficult for spouses to work through the feelings surrounding mourning and loss, because society does not recognize the feelings of loss when a loved one's personality changes. Lezak notes that it is difficult for spouses who feel they cannot cope with the situation to seek a divorce. If the marriage was satisfactory before the injury, feelings of responsibility, guilt, and fear of social condemnation may add to the reluctance of spouses to divorce their injured partners. Lezak (1988) also suggests that when a partner in a stable marriage sustains a severe head injury, their spouse loses a close companion, and one of their major sources of emotional support and affection, at a time when this support is most needed.

Bond (1984) found that wives of older men with traumatic brain injuries are more likely to stay with their husbands. This would suggest that younger, more recently married couples may be less able to cope with the effects of brain injuries than older couples.

Rosenbaum and Najenson (1976) studied married couples in which the husbands were Israeli soldiers who were disabled by traumatic brain injuries. This study compared the burden and reactions of wives of soldiers with traumatic brain injuries to those of wives of men with spinal cord injuries. The results demonstrate that, while both groups of wives experienced considerable stress during the first year following the injury, greater stress was experienced by the wives of men with brain injuries. The spouses of men with brain injuries reported decreased leisure time, fewer contacts with friends, and greater disruption of their marital relationships. They also felt less able to share household, childrearing, and financial responsibilities with their now disabled husbands. The increased responsibilities and loss of social activities were associated with depressed mood in the wives.

No studies in the literature have investigated dyadic adjustment as a resource for wives in terms of their ability to adapt to their new circumstances following their husbands' brain injuries. Lavee, McCubbin, and Olson (1987) did, however, investigate dyadic adjustment in relation to the Resiliency Model. They examined a multivariate model of the effect of life events and transitions, intrafamily strain, dyadic adjustment, and appraisal on family well-being. These researchers found that dyadic adjustment was positively related to well-being, thereby counteracting the effect of the "pile-up of demands". They conclude that dyadic adjustment is a mediating factor between demands and well-being. In this study the level of dyadic adjustment was considered a resource in terms of womens' ability to adapt to the effects of their husbands' brain injuries.

Social support

McCubbin and McCubbin (1991) identify a variable in their model that they term "community resources and supports". They suggest that of all the community resources referenced in the study of family adaptation, the one that has received the most attention in the stress literature is social support. Social support is most often viewed as one of the primary buffers or mediators between stress and health breakdown. Although there are many conceptualizations of social support, McCubbin and McCubbin (1991) cite Cobb's (1976) definition as the one most useful for consideration in the context of the Resiliency Model. Cobb (1976) defines social support as information exchanged at the interpersonal level that provides (a) emotional support, which leads the individual to believe that he or she is cared for and loved; (b) esteem support, which leads the individual to believe that he or she is esteemed and valued; and (c) network support, which leads the individual to believe that he or she belongs to a network of communication involving mutual obligation and mutual understanding. McCubbin and McCubbin (1991) expand on Cobb's three forms of support to include (a) appraisal support, which is information in the form of feedback allowing the individual to assess how well he or she is doing with life's tasks, and (b) altruistic support, which is information received in the form of goodwill from others for having given something of oneself.

Generally, the role of social networks in mediating the effects of stress is well established in the literature. Unger and Powell (1980), in their review of sociological and psychological studies, examined the strong positive relationship between social networks and a family's adaptation to societal crises, life transitions, and family conflicts. These researchers found that when families are in need of help they typically do not seek initial aid from formal organizations even if the organization is designed to serve the individual's presenting problem.

Vargo (1983) studied the adaptation to disability by the wives of men with spinal cord injuries, using a phenomenological approach. The presence of adequate, functional support systems was the single most important factor in the way in which these women reacted. When these support systems were active and functioning well, the effect was positive; when they were absent or functioning poorly, the effect was negative.

There are numerous studies in the literature on caring for individuals with Alzheimer's disease which emphasize the importance of social support (Aronson et al., 1984; Cantor, 1983; Gilhooley, 1984; Haley, Levine, Brown, & Bartolucci, 1987; Quayhagen & Quayhagen, 1988; Sistler, 1989). Zarit, Reever, and Bach-Petersen (1980) note that caregivers who received support from family and friends perceived less burden than caregivers who did not receive support. George and Gwyther (1986), in their study of family caregivers of demented adults, indicate that 59% of the 510 caregivers surveyed expressed a need for more assistance from family and friends. Scott et al. (1986) report that socio-emotional support from family members is positively associated with more effective coping styles in Alzheimer's caregivers.

Dring (1989) discusses caregivers who care for family members with cognitive dysfunctions as a result of brain injuries and suggests that one of the stresses for caregivers is that social relationships are difficult to maintain and social isolation can develop. Many caregivers fulfill their role with little assistance from others. Dring (1989) also suggests that the "perception of adequate support correlates strongly with caregiver well-being" (p. 43). Characteristics of the caregiving situation and resources available to caregivers directly affect caregivers' well-being. Social isolation can lead to physical and mental deterioration of caregivers and, therefore, social support for caregivers is essential.

Liss and Willer (1990) suggest that caregivers have less time to restore their own social networks, which increases their degree of social isolation. This may be particularly problematic for a woman, who now may need someone other than her husband for support and companionship, but is limited by the time available to facilitate social contacts.

Jacobs (1989a) suggests that individuals with brain injuries may experience reduced comprehension of social conventions. The injured individual's behavioral changes become obstacles to effective social interaction and are related to decreases in friendships (Jacobs, 1989a). Combined with a post-injury decrease in the number of social outlets, it is not surprising that surveys have reported that 21% to 38% of individuals with brain injuries are socially isolated (Jacobs, 1989a). Many individuals with brain injuries become dependent upon their families to meet their social needs, which increases family burden.

Mauss-Clum and Ryan (1981) found that many families describe relatives and friends as having been a more helpful source of support and information than rehabilitation staff. These findings underscore the need to investigate social support as a potential resource for women following their husbands' brain injuries.

No studies in the literature have specifically investigated the relationship between social support and the adaptation of women married to men with brain injuries. This study investigated the variable of social support in relation to the adaptation of women following their husbands' brain injuries.

Coping

McCubbin and McCubbin (1991) suggest that the process of acquiring and allocating resources for meeting demands is a critical aspect of the adaptation response. This process is the Adaptive Coping variable in their Resiliency Model. In the context of their model they define a coping behavior as "a specific effort (covert or overt) by which an individual (or group of individuals such as the family) attempts to reduce or manage a demand on the family system" (p. 22). McCubbin and McCubbin (1991) further suggest that coping serves to maintain or restore the balance between demands and resources. Coping can occur at an individual, family, or community level. McCubbin and McCubbin (1991) identify five ways in which adaptive coping can occur:

1. Coping can involve a direct action to reduce the number and/or intensity of demands. This may involve a woman returning to work in order to reduce financial strain on the family.

2. Coping can involve direct action to acquire additional resources not already available to the family. This may involve a woman attending a support group for families with members who have sustained brain injuries.

3. Coping can involve the maintenance of existing resources so they can be allocated and reallocated to meet changing demands. This may involve maintaining ties which provide social support.

4. Coping can involve managing the tension associated with ongoing strains. This may involve a woman taking time out from the responsibilities at home to take care of herself.

5. Coping can also involve appraisal to change the meaning of a situation to make it more manageable. This may involve a woman reducing her expectations of her husband. This may also involve maintaining optimism and accepting that this is the best one can do given the circumstances.

McCubbin and McCubbin (1991) suggest that family coping can be viewed as coordinated problem-solving behavior of the whole system or complementary efforts of individual family members.

Kaplan, Smith, Grobstein, and Fischman (1973) studied coping with the stress imposed by a severe illness. They suggest that more must be learned about effective individual and family coping and more help given to improve this coping. A better understanding of the process of coping with severe stress would have substantial clinical and preventive value. Adaptive coping by the family and its' individual members offers the greatest protection for family members confronted by stressful situations, and the best assurance that the family will continue as a unit, able to meet the changing needs of its' members.

Quayhagen and Quayhagen (1988), in discussing caregivers of individuals with Alzheimer's disease, suggest that coping with the devastation of brain injuries can severely tax families' resources. They suggest that the stress engendered by personal, social, and financial changes can alter a family's ability to cope and, subsequently, the well-being of its' members. They further suggest that the added responsibilities of caregivers increased their need for effective coping strategies and social supports.

Coping with the impact of brain injuries is described in the rehabilitation literature as one of the most difficult tasks that can confront a family (Lezak, 1978; Oddy, 1984). Grinspun (1987) suggests that during the injured person's rehabilitation, considerable emphasis is placed on teaching family members about the nature of the injury and its' consequences and assisting them in the coping process. However, there is evidence that many families feel ill prepared for the problems they encounter at home (Oddy et al., 1978a, 1978b).

A few studies have investigated coping strategies employed by a close relative in relation to a family member with a brain injury. Klonoff and Prigatano (1987) conceptualize coping styles along two broad dimensions (a) functional/expected and (b) dysfunctional. These researchers suggest that, in the former, despite the natural reactions of shock, sadness, and bitterness, the family eventually adapts to the existence of a relative with a brain injury. In the latter, the individual with the brain injury often becomes the focus of the family or the family reacts with denial and unacceptance of the consequences of the injury.

Karpman, Wolfe, and Vargo (1985) explored, through indepth interviews, the process of psychological adjustment of the parents of 10 adults who had sustained brain injuries. Content analysis resulted in 12 themes, several of which can be viewed as "coping strategies", including maintaining a positive attitude; hope and optimism; a strong belief in religion; resistance, perseverance, and internal strength; cohesion and cooperation within the family; and an external support system. Karpman et al. (1985) conclude that additional studies are needed to empirically validate the themes derived in their study with other special needs groups and to implement and evaluate intervention programs aimed at assisting both injured individuals and their families with the process of adjustment.

Willer et al. (1991) report on the problems and coping strategies of individuals with traumatic brain injuries and their spouses. Their subjects included 20 men and 11 women with traumatic brain injuries and their respective spouses. All injured subjects had experienced severe head injuries one and a half or more years earlier. A structured small group discussion process was used to generate a list of problems and coping strategies. The coping strategies of women whose husbands had suffered brain injuries, in descending order of effectiveness were (a) a process of identifying problems in a realistic but optimistic manner, (b) becoming assertive in dealing with the daily obstacles they encountered, (c) encouraging increased independence of their husbands, (d) getting away from family pressures and taking time for themselves, and (e) their own participation in support groups.

No studies in the literature have systematically investigated the level of coping of the wives of individuals with brain injuries or the relationship between coping and level of adaptation. This study investigated the relationship between the overall level of coping (and particular coping strategies) and the level of adaptation of women married to men with brain injuries.

Adaptation of the Wives

McCubbin and McCubbin (1991) describe family adaptation as the central concept in the Adaptation phase of their Resiliency Model. Family adaptation is defined as a "minimal discrepancy between demands and capabilities at two primary levels of interaction: individual to family and family to community. . . ." (p. 319). Family adaptation is, therefore, a concept which describes a continuum of outcomes that reflect efforts to achieve a balance at these two levels of functioning (individual to family and family to community). McCubbin and Patterson (1983) describe the positive end of this continuum as bonadaptation and suggest that it is characterized by the maintenance and strengthening of family integrity, a continued promotion of individual member and family unit development, and the maintenance of family independence and a sense of control over environmental influences. The negative end of the continuum, family maladaptation, is characterized by the deterioration of family integrity, a curtailment or deterioration in an individual member's physical and/or psychological development, a deterioration in the quality of family relationships, and/or the loss or decline of family independence and autonomy.

In Vargo's (1983) study 10 women, whose husbands had sustained spinal cord injuries after their marriage, were interviewed using an open-ended questionnaire format. Sixteen major themes emerged from the content analysis of the interviews. In relation to the process of adaptation, six factors emerged as being of primary importance to a satisfactory outcome including support systems, commitment to the marital relationship, hope, staff attitudes and advice, architectural/societal barriers, and children.

Wilson (1990) examined the mental well-being and special problems of 188 elderly wives identified as the primary caregivers of their disabled husbands and reports that "women who care for a disabled spouse face a contagion of stress that severely impairs their sense of well-being and satisfaction" (p. 418).

Several studies in the literature have looked at the "effects" of brain injuries on female relatives of injured males. The "effects" of brain injuries on the relatives are usually measured in terms of standard measures of mood, symptomology, or psychopathology. Rosenbaum and Najenson (1976) compared reports of wives of individuals who had sustained open and closed brain injuries to wives of paraplegics and normal controls, 1 year post-injury. The wives of the individuals with brain injuries reported increased depression, significant losses in their social lives, and a reduction in sexual activity. Lezak (1978) reports that spouses of individuals with brain injuries experience significant role changes, often cannot divorce with dignity or good conscience, and have frustrated sexual and affection needs. Livingston et al. (1985) assessed 57 men who had sustained severe brain injuries and a female relative at 3, 6, and 12 months post-injury. Their findings indicate that although the relatives' functioning was good initially, problems began to develop at 3 months post-injury. At 3 and 6 months as many as 40% of the relatives had a high probability of having a psychiatric illness (as measured by the General Health Questionnaire). This is twice the level of psychiatric dysfunction found in the general population.

Rather than investigating the "effects" of husbands' brain injuries on women in terms of indicators of mood, symptomology, or psychopathology, this study investigated the womens' levels of adaptation using a measure of well-being developed by McCubbin and Patterson (1982).

Purpose and Rationale

The purpose of this study was to investigate the process of adaptation of women following their husbands' brain injuries. These women were asked two open-ended questions regarding the effects of their husbands' brain injuries and the ways in which they had dealt with these effects. In addition, six variables related to the process of adaptation were investigated including (a) the levels of psychosocial functioning of the husbands as measured by an adaptation of the Portland Adaptability Inventory (Lezak, 1987), (b) the levels of subjective burden of the women as measured by the Subjective Burden Scale (McKinlay et al., 1981), (c) the levels of dyadic adjustment of the women as measured by the Dyadic Adjustment Scale (Spanier, 1976), (d) the levels of social support of the women as measured by the Social Support Inventory (McCubbin et al., 1982), (e) the levels of coping of the women as measured by the Family Crisis Oriented Personal Evaluation Scales (McCubbin et al., 1981), and (f) the adaptation of the women as measured by the Family Member Well-being Index (McCubbin & Patterson, 1982). A study of spousal adaptation following brain injury would make a valuable and significant contribution to the literature and assist rehabilitation professionals in the development of more effective strategies (both individual and group) to assist women to cope with and adapt to the consequences of having husbands with brain injuries. This would, in turn, facilitate the rehabilitation of the husbands and reinforce the need for the development of programs for the ongoing support of the wives and families of men with brain injuries.

The following limitations applied to the proposed study. Only the wives of men who had sustained brain injuries were investigated. The husbands of women who had sustained brain injuries were not studied. As the self-report measures were completed by wives it is their perceptions of the circumstances which were investigated.

Hypotheses

In a situation of change following a husband having sustained a brain injury:

1. The husband's level of psychosocial functioning will be positively related to his wife's level of well-being.
2. The wife's level of subjective burden will be negatively related to her level of well-being.
3. The wife's level of dyadic adjustment will be positively related to her level of well-being.
4. The wife's level of social support will be positively related to her level of well-being.
5. The wife's level of coping will be positively related to her level of well-being.

An alpha level of $p < .05$ will be deemed necessary to reject the null hypotheses.

Research Questions

In addition to the above hypotheses, the following research questions were examined in order to gain a better understanding of the experiences of women married to men with brain injuries:

1. What are the effects on women of their husbands' brain injuries?

2. How do women deal with the effects of their husbands' brain injuries?

3. What are the levels of psychosocial functioning (as measured by an adaptation of the Portland Adapability Inventory) of the men with brain injuries, as perceived by their wives?

4. What are the levels of subjective burden (as measured by the Subjective Burden Scale) reported by the wives of men with brain injuries?

5. What is the relationship between the womens' levels of subjective burden and their husbands' levels of psychosocial functioning?

6. How do the levels of subjective burden reported by the wives of men with brain injuries compare with the findings of other researchers using the Subjective Burden Scale?

7. How do the wives of individuals with brain injuries compare with the normative group in terms of dyadic adjustment (as measured by the Dyadic Adjustment Scale)?

8. t level of social support do the women in this study experience (as measured by the Social Support Inventory)?

9. What is the primary kind of social supoort the women in this study receive?

10. Who provides the majority of social support to the women in this study?

11. In terms of coping (as measured by the Family Crisis Oriented Personal Evaluation Scales) how do the women in this study compare with the normative sample?

11. What levels of well-being do the women in this study experience (as measured by the Family Member Well-being Index)?

12. How do the women in this study compare with the normative group in terms of well-being?

CHAPTER 3 - METHODOLOGY

Introduction

The purpose of this study was to investigate the process of adaptation of women following their husbands' brain injuries. A telephone interview was conducted with each woman in order to gather demographic and brain injury related information. In addition, these women were asked two open-ended questions regarding the effects of their husbands' brain injuries and the ways in which they had dealt with these effects. Six variables related to the process of adaptation were investigated by means of self-report measures completed by the women. These variables included the husbands' levels of psychosocial functioning and the womens' levels of subjective burden, dyadic adjustment, social support, coping, and well-being.

In the following chapter, the methods used to identify women willing to participate in the study and the criteria for selecting the sample of women are presented. The procedures for data collection and the instruments used are also described. Finally, the methods of data analysis are outlined.

Subjects

The women who participated in this study were selected on the basis of the following criteria: married to husband prior to his sustaining a brain injury, the husband was between the ages of 25 and 65, the brain injury occurred at least 1 year prior to the collection of data, the woman was living with husband at the time of data collection, and willingness to participate. Subjects were contacted with the assistance of the Northern Alberta Brain Injury Society (NABIS), the Glenrose Rehabilitation Hospital (GRH), and the Workers' Compensation Board (WCB). The study underwent ethical review by the Department of Educational Psychology's ethics review committee, the Glenrose Rehabilitation Hospital's ethics review committee, and the Workers' Compensation Board's ethics review committee.

Procedure

Pilot Study

For the pilot study, a letter was sent to potential participants identified by NABIS. This letter provided information regarding the study and invited the women to participate in the study by calling the researcher. Five women participated in the pilot study. The pilot study followed the same format as outlined below. The primary purpose of the pilot study was to obtain feedback regarding both the telephone interview and the self-report measures.

Telephone Interview

Lists of men who had sustained brain injuries were generated by the GRH and the WCB. These lists included men between the ages of 25 and 65 years at the time of injury, who were married or living with a woman at the time of injury, and who had sustained brain injuries at least 1 year prior to the collection of data. Lezak (1987) suggests that it typically takes 6 months to 1 year for family members to realize the extent and possible permanence of the problems of the individual with the brain injury. The wives of the identified males were initially contacted by letter. The letter from the GRH went out from the physician on the Brain Injury Rehabilitation Program. The letter from the WCB went out from the Manager of Special Projects. These letters informed the potential participants that a psychologist at the GRH was interested in conducting research with women who were married to men who had sustained brain injuries. If they did not wish to be contacted by the researcher they were asked to call and leave their name with the physician's secretary (GRH) or the WCB manager. These names were then deleted from the lists. After the potential subjects had been given time to decline participation, the lists were given to the researcher. The researcher contacted by phone all of the potential subjects on the revised lists. During the phone call the researcher provided further information regarding the study and invited the women to participate in the study. For those women who agreed to participate, a convenient time was arranged in order to conduct the telephone interview. The telephone interview (Appendix A) included the following: (a) questions regarding demographic information (age, length of time married, number of children living at home, education, work status, occupation, change in income level since the brain injury, degree of financial strain, change in role(s) for the woman following the brain injury, and background and medical information concerning the brain injury; (b) two open-ended questions concerning the positive and negative effects of the brain injury on the woman and the ways in which she dealt with these effects; (c) the Portland Adaptability Inventory (PAI) (Lezak, 1987) (revised for use in a telephone interview format) as a measure of the level of psychosocial functioning of the husband, and (d) the Subjective Burden Scale (SBS) (McKinlay et al., 1981) as a measure of subjective burden.

Self-Report Measures

Following the telephone interview a package of information was mailed to the participants. The package included a cover letter (Appendix B), a consent form (Appendix C), four self-report measures, and a second administration of the Subjective Burden Scale. The cover letter included the name and phone number of the researcher in the event of any questions or concerns. The women were asked to return the completed self-report measures in a prepaid envelope.

Instrumentation

Telephone Interview

The telephone interview included questions regarding demographic information, two open-ended questions, and questions from two inventories. The two open-ended questions were (a) Please list the ways (positive or negative) in which your husband's brain injury has affected you and (b) Please list the ways in which you have dealt with your husband's brain injury. The two inventories are described below.

Psychosocial functioning of the husbands.

A modified version of The Portland Adaptability Inventory (PAI) (Lezak, 1987) was used to assess the levels of psychosocial functioning of the husbands. The levels of psychosocial functioning of the husbands were considered to be one aspect of the "pile-up of demands" (variable AA) in the Adaptation phase of McCubbin and McCubbin's (1991) Resiliency Model (see Figure 1). The PAI was developed following the broad outlines of a similar behavioral inventory offered by Bond (1975) but it was modified by Lezak to deal with both the short and long-term behavioral and social adjustment problems of individuals with brain injuries and with the psychometric requirements of such an instrument (Lezak & O'Brien, 1988). An instrument specifically designed to examine problems relevant to individuals with brain injuries avoids the potential biases of objective tests which typically have been standardized on normal or psychiatric samples. This instrument was designed to be used by a professional in a face to face interview format. The questions were revised in order to be used as part of a telephone interview.

Subjective burden of the wives.

The levels of subjective burden experienced by the women were measured by the Subjective Burden Scale developed by McKinlay et al. (1981). Subjective burden is assessed using a simple 7-point rating scale ranging from: (1) I feel no strain or distress as a result of the changes in my husband/partner to (7) I feel severe strain or distress as a result of the changes in my husband/partner. The responses to the scale are divided into low, medium, and high levels of subjective burden. The subjective burden was a second measure of the "pile-up of demands" (variable AA) in the Resiliency Model.

Self-Report Measures

Four self-report measures were included in the mail-out package. Each self-report measure assessed a separate variable of the Adaptation phase of McCubbin and McCubbin's (1991) Resiliency Model. These measures are described below.

Dyadic adjustment.

Dyadic adjustment was measured by the Dyadic Adjustment Scale which is a 32-item instrument developed by Spanier (1976). Dyadic adjustment was considered a potential resource for the woman and was, therefore, a measure of the "family strengths, resources, and capabilities" (variable BB) in the Resiliency Model (see Figure 1). This instrument is designed to assess the quality of an intimate relationship as perceived by married or cohabiting couples. The instrument can be used as a general measure of satisfaction in the relationship by using total scores. Factor analysis indicates that the instrument measures four aspects of the relationship, dyadic satisfaction (DS), dyadic cohesion (DCoh), dyadic consensus (DCon), and affectional expression

(AE). As a total score, the DAS has an internal consistency of alpha = .96. The subscales have the following internal consistencies: DS = .94, DCoh = .81, DCon = .90, and AE = .73. The instrument has been checked with logical content validity procedures. It has shown known-group validity by discriminating between married and divorced couples on each item. It also has evidence of concurrent validity, correlating with the Locke-Wallace Marital Adjustment Scale. The DAS was normed on a sample of married (n=218) and divorced persons (n=94).

Social support.

The Social Support Inventory (SSI) (McCubbin et al., 1982) is a 60-item inventory which was used as a measure of social support. In the Resiliency Model this is considered to be an aspect of "community resources and supports" (variable BBB) (see Figure 1). This scale taps five kinds of affective support and 12 sources of support. The kinds of support are emotional, esteem, network, appraisal, and altruistic, and are patterned after the original conceptions of Cobb (1976). The sources of support include spouse or partner, children, other relatives, friends, co-workers, community groups, church, spiritual faith, professionals and service providers, special groups (designed to help with specific problems or responsibilities), books and television, and other. Respondents indicate on a 3-point scale whether they receive each of the kinds of affective support from each of the sources. The scale yields a support score for each of the five kinds of support, 12 sources of support, and a total support score. Limited normative data is available from the authors. A test-retest reliability coefficient of .81 is reported by the authors. Evidence for construct validity is provided by a systematic literature review, 22 ethnographic interviews, and completion of the SSI by the same 22 subjects.

Coping.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin et al., 1981) was used to assess coping. This inventory was used to measure the "coping" variable (variable PSC) in the Resiliency Model (see Figure 1). The F-COPES is a 29-item, 5-point self-report inventory. Factor analytic procedures resulted in five scales. Internal consistency reliability estimates for the five scales are (a) acquiring social support, .83; (b) reframing, .82; (c) seeking spiritual support, .80; (d) mobilizing family to acquire and accept help, .71; and (e) passive appraisal, .63. The alpha reliability for the total scale is .86. Test-retest reliability of the entire scale is .81.

Well-being.

The Family Member Well-being Index (FWBI) (McCubbin & Patterson, 1982) was used to measure the adaptation of the women. McCubbin and McCubbin (1991) identify the variable of "level of adaptation" (variable XX) in their model (see Figure 1). The FWBI is an eight item index. It was developed as a reliable (Alpha = .86) and valid index of the degree to which a family member has adapted to their circumstances in terms of concern about health, tension, energy, cheerfulness, fear, anger, sadness, and general concern (McCubbin, 1991).

Data Analyses

Qualitative Analyses

The two open-ended questions asked during the telephone interview were (a) Please list the ways (positive or negative) in which your husband's brain injury has affected you; and (b) Please list the ways in which you have dealt with your husband's brain injury. All statements in response to these two open-ended questions were recorded and form the basis for the qualitative analyses. The first list includes those statements which indicate the positive effects for the women of their husbands' brain injuries. The second list includes those statements which pertain to the negative effects for the women of their husbands' brain injuries. The third list includes those statements which pertain to the ways in which the women dealt with their husbands' brain injuries.

In the first analysis these statements were grouped by the researcher into very specific themes, based on similarity of content and meaning. In the second analysis these themes were regrouped by the researcher into broader themes, again based on similarity of content and meaning. To verify these themes a second researcher independently carried out the same procedure. Where inconsistencies in theme were found between raters these were further reviewed until consensus on the nature of the themes was established. In the third analysis the themes of the positive and negative effects of brain injuries were combined and grouped into general themes with subthemes and the ways in which the women dealt with the brain injuries were grouped into general themes.

Quantitative Analyses

Seventy-six women were interviewed and 62 women returned completed self-report measures. With 62 subjects a correlation of .21 was needed to be statistically significant presuming directionality in line with the stated hypotheses. There were three components to the data analysis (a) descriptive statistics (percents, frequencies, means, standard deviations, and ranges) on the telephone interview and self-report data, (b) comparisons of the self-report data with normative data, and (c) correlations among all of the measures.

CHAPTER 4 - RESULTS

Introduction

The results of the investigation are presented in this chapter. The sample of women participating in the study are described. Summary statistics (e.g., percents, frequencies, means, standard deviations, and ranges) are presented for the demographic data . The results of the qualitative analyses of the two open-ended questions from the telephone interview (regarding the effects of the brain injuries on the women and the ways in which they dealt with these effects) are described. Correlations among the scores on the six self-report measures are examined. Summary statistics are presented for each of the self-report measures and where possible the results are compared with existing normative data. Correlations among the scores on the self-report measures and a number of demographic variables are also examined. In addition, the results of comparisons between women who completed the self-report measures and those who did not, as well as between women married to men with traumatic brain injuries versus other types of brain injuries are reported. And finally, reliability data on the self-report measures are presented.

Demographics

The names of potential subjects were generated by the Northern Alberta Brain Injury Society (NABIS), the Glenrose Rehabilitation Hospital (GRH), and the Workers' Compensation Board (WCB). Subjects had to meet the following criteria for inclusion in the study (a) the husband or partner's brain injury occurred at least 1 year prior to collection of data, (b) the woman was married to or living with the man at the time of his brain injury (c) the woman was living with the man at the time of data collection, and (d) the man was between the ages of 25 and 65. Since the woman had to be married to or living with the man, women who were divorced, separated, or widowed were excluded. Women whose husbands were living in extended care centers or brain injury rehabilitation facilities were also excluded, since they were not living with their husbands.

Following the initial attempt to contact the individuals whose names were provided to the researcher by the various organizations, many were found to be inappropriate for inclusion in the study or declined to participate. Of these individuals, 4 lived out of Albena, 19 had moved and could not be found, 13 declined to participate, 6 had sustained a brain injury within the past 12 months, and 4 were deceased.

Of the 84 women who were interviewed, 8 were excluded from the study due to the following reasons: 4 womens' husbands were not living at home; 3 womens' husbands had sustained their brain injuries less than 1 year prior to contact; and 1 woman's husband had been diagnosed with schizophrenia prior to his having sustained a brain injury. Of the remaining 76 women, 62 (81.6%) returned completed self-report measures.

A number of demographic variables were recorded in order to describe the sample of 62 women and their husbands. The means, standard deviations, percents, and frequencies for these variables are found in Table 1. The women ranged in age from 27 to 58 with an average of 42.2 years. Their husbands ranged in age from 30 to 62 with an average of 45.1 years. The couples had been married (or cohabiting) from 1 to 38 years with the average being 19.6 years. The number of children at home ranged from 0 to 4. Eighty-one percent of the women had children at home. With respect to the level of education of the women: 29% had 7 - 11 years, 38.7% had completed high school, 17.7% had some college or university, and 14.5% had completed college or university. With regard to the husbands' levels of education: 3.2% had less than 6 years of formal education, 43.5% had between 7 and 11 years of education, 24.2% had completed high school, 11.3% had some college or university, and 17.7% had completed college or university. With respect to employment: 58.0% of the women were employed outside the home (either full or parttime) and 41.9% were fulltime homemakers. With regard to their husbands: 24.2% were employed (either full or parttime) and 75.8% were unemployed because of their disability. Of the women who worked outside the home: 66.7% were classified as blue collar or clerical workers, 22.2% were skilled workers, and 11.1% were professionally employed. With regard to the men's occupations, (reported as prior to their brain injury if presently unemployed), 53.2% were blue collar workers, 37.1% were skilled workers, and 9.7% were professionals. Almost three-quarters of the women (72.6%) indicated that their family income had

Table 1

Percent and Frequency Data for the Demographic and Accident Information (n=62)

		Mean	SD	Range
Age:	Women	42.2	7.8	27-58
	Husbands	45.1	8.6	30-62
Number of years of marriage (cohabitation)		19.6	9.9	1-38

Number of children living at home:	%	(f)
0	19.4	(12)
1	35.5	(22)
2	27.4	(17)
3	12.9	(8)
4	4.8	(3)

Number of years of education:	Women		Husbands	
	%	(f)	%	(f)
1. 0-6	0	(0)	3.2	(2)
2. 7-11	29	(18)	43.5	(27)
3. High school	38.7	(24)	24.2	(15)
4. Some college/university	17.7	(11)	11.3	(7)
5. Completed college/university	14.5	(9)	17.7	(11)

table continues

Employment:	Women		Husbands	
	%	(f)	%	(f)
1. Working full-time	40.3	(25)	17.7	(11)
2. Working part-time	17.7	(11)	6.5	(4)
3. Homemaker	41.9	(26)	0	(0)
4. Unemployed	0	(0)	75.8	(47)

Occupation:	Women		Husbands	
(former occupation of man if unemployed)	%	(f)	%	(f)
1. Homemaker	41.9	(26)	0	(0)
2. Blue collar worker	38.7	(24)	53.2	(33)
3. Skilled worker	12.9	(8)	37.1	(23)
4. Professional	6.5	(4)	9.7	(6)

Change in family income since the injury:	%	(f)
1. Increased	9.7	(6)
2. Decreased	72.6	(45)
3. Stayed the same	17.7	(11)

table continues

Please circle one of the responses to the right for each of the following statements:

	Strongly Disagree		Moderately Disagree		Neutral		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
We are experiencing financial strain.	24.7	(15)	22.6	(14)	0	(0)	17.7	(11)	35.5	(22)
There has been a change in my role(s) in the family following my husband/partner's brain injury.	6.5	(4)	4.8	(3)	0	(0)	17.7	(11)	71	(44)

	M	SD	Range
Months post injury:	60.9	60.9	12 - 258

Type of Injury:

	%	(f)
1. TBI	71.0	(44)
2. Stroke	24.1	(15)
3. Tumor	3.2	(2)
4. Hydrocephalus	1.6	(1)

table continues

	Yes		No		dk	
	%	(f)	%	(f)	%	(f)
Skull fracture:	30.6	(19)	61.3	(38)	8.1	(5)
Brain surgery:	37.1	(23)	61.3	(38)	1.6	(1)

decreased following their husbands' brain injuries. Just over half of the women (53.2%) indicated that they were experiencing financial strain. In relation to role change, 88.7% of the women agreed that there were changes in their roles following their husbands' brain injuries.

The number of months since the husbands' brain injuries ranged from 12 to 258 months, with an average of 60.9 months. The types of brain injuries were classified into two broad categories, traumatic brain injuries and other types of brain injuries. Seventy-one percent of the men had sustained traumatic brain injuries. Of the "other" category: 24.1% of the men had sustained stroke related injuries (aneurysms, ateriovenous malformations, blood clots), 3.2% had tumors, and 1.6% had hydrocephalus. For those women who knew, they reported that 33.3% of their husbands had sustained skull fractures and 37.7% of the men had undergone some type of brain surgery.

Qualitative Analyses of Open-Ended Questions

The telephone interview included two open-ended questions (a) Please list the ways (positive or negative) in which your husband's brain injury has affected you and (b) Please list the ways in which you have dealt with your husband's brain injury. From these two open-ended questions asked during the 76 telephone interviews, a total of 716 statements were collected. These statements are found in Appendix D. The first list includes those statements which indicate the positive effects for the women of their husbands' brain injuries and is comprised of 58 statements. The second list includes those statements which pertain to the negative effects for the women of their husbands' brain injuries and is comprised of 340 statements. The third list includes those statements which pertain to the ways in which the women dealt with their husbands' brain injuries and is comprised of 305 statements. There were an additional 13 statements which did not appear relevant to the questions asked and, therefore, did not fit into any of the lists.

In the initial analysis these statements were grouped by the researcher into very specific themes based on similarity of content and meaning. The statements which pertain to the positive effects fell into 22 specific themes. The statements regarding the negative effects fell into 33 specific themes. The statements which pertain to the ways in which the women dealt with the effects of the brain injuries fell into 66 specific themes. The initial themes and statements appear in Appendix E.

In the second analysis the specific themes were regrouped by the researcher into broader themes, based on similarity of content and meaning. The positive effects of the brain injuries fell into five themes. The negative effects of the brain injuries fell into five themes. The ways in which the women dealt with the brain injuries fell into four themes. These themes and statements are listed in Appendix F.

In the third analysis it was found that there was considerable overlap between the general themes of the positive and negative effects of brain injuries. In combining the general themes from these two categories, five general themes with several subthemes were derived. These general themes and subthemes (for question 1) are listed in Table 2. The ways in which the women dealt with the brain injuries (question 2) fell into four general themes which are listed in Table 3.

Table 2

General Themes and Subthemes Derived from the First Open-Ended Question.

"Please list the ways (positive or negative) in which your husband's brain injury has affected you"

1. Changes in the husbands
2. Changes within and for the women:
    a. positive changes regarding personality qualities and attributes
    b. an increase in stress
    c. an increase in negative feelings

table continues

3. Changes in relationships:
    a. marital
    b. with the children
    c. within the family
4. Changes in lifestyle (positive and negative)
5. Feelings of support or feelings of a lack of support.

Table 3

General Themes Derived from the Second Open-Ended Question.

"Please list the ways in which you have dealt with your husband's brain injury"

1. Activities
2. Support
3. Behaviors, thoughts, attitudes, outlooks (positive and negative)
4. Faith

The general themes and subthemes for the two open-ended questions will now be discussed in greater depth along with examples of the types of statements they represent. It is important to note that the themes and subthemes are indicative of broad categories and that there is overlap between these categories.

First Open-Ended Question

In relation to the first open-ended question "Please list the ways (positive or negative) in which your husband's brain injury has affected you" the following general themes and subthemes were derived. The first general theme referred to changes in the husbands. Most of the women described various changes in their husbands. These changes were described as negative and included changes in personality, emotionality, cognition (primarily memory), and physical functioning. Examples of statements which best illustrate this theme are:

1. He gets frustrated easily and his temper is uncontrollable at times.
2. What was affected was his ability to control his emotions.
3. There are a lot of things he can't do physically.
4. His personality has changed completely.
5. He has memory problems.

The changes in their husbands and their changed circumstances resulted in a number of changes for the women. The second general theme, therefore, referred to changes within and for the women. The three subthemes within this theme included (a) positive changes with regard to personality qualities and attributes, (b) increased stress, and (c) increased negative feelings. Many of the women expressed the sentiment that the injury and subsequent disability of their husbands had produced positive changes in themselves. Some of these changes, such as the feeling of being emotionally stronger, may not be so much change as increased awareness of one's ability to deal with a crisis and its' consequences. Statements which best illustrate this subtheme are:

1. I'm no longer shy and withdrawn. It brought me out of my shell.
2. I have become much stronger.
3. I became a more caring person.
4. Made me more independent.

The second subtheme referred to an increase in stress for the women due to increased responsibilities. Responsibilities were relegated to them which they may never have had the opportunity (or desire) to handle before, things such as finances, household and car repairs, and yardwork. Examples of statements which best illustrate this subtheme are:

1. It is very stressful. There are a lot of worries and concerns and it's hard to take.
2. As a result of the injury there are so many more responsibilities.
3. It gave me so many new roles to play.

4. All the heavy work is mine now.

The third subtheme had to do with an increase in negative feelings and attitudes experienced by the women. Several women described a variety of negative feelings in relation to the changes in their husbands. Some women described feelings of guilt in relation to not liking the "different" men they were now living with. Other women described increased worry in relation to their husbands' decreased abilities to function independently. Still other women described a need to protect themselves from the consequences of the character changes in their husbands such as verbal abuse, insensitivity, and criticism directed towards them. Examples of statements which best illustrate this subtheme are:

1. I've dealt with a lot of guilt because I didn't like him anymore.

2. I worry about him.

3. I've become "hard" as an insulation for myself so I don't get hurt by my husband's actions and words.

In addition to the changes experienced by the women in relation to themselves, many women described changes in their marital relationships and in their husbands' relationships with others. The three subthemes in this category included (a) changes in the marital relationship, (b) changes in both the husbands' and womens' relationships with their children, and (c) changes within the family as a whole. With regard to the first subtheme, changes in the marital relationship, the statements could be separated into both positive and negative examples. On the positive side several women felt fortunate that their husbands had not died as a result of their injuries. This experience made them more appreciative of their husbands. Examples of statements which best illustrate this subtheme are:

1. I don't take him for granted anymore.

2. I care about him more than before.

In terms of the negative aspects of this subtheme the statements tended to relate to both the marital relationship in general and the sexual relationship specifically. As a result of the changes in their husbands many women reported that their husbands could not function adequately as equal marital partners. Many women indicated that their husbands had regressed to a childlike state of dependency. For some men this change resolved over time but for others it appeared to be a permanent change. Examples of statements which best illustrate the negative aspects of this subtheme are:

1. I don't have an equal partner because he can't make decisions or be supportive.
2. He was unable to assume his role as a spouse.
3. My relationship has become maternal - I have three sons instead of two.
4. I'm frustrated sexually.

The second subtheme referred to changes in the husbands' interactions with their children or changes in the ways in which the women interacted with their children, as a result of the changes in their husbands. Changes in the husbands, in terms of cognitive and emotional functioning, seemed to result in their inability to relate to their children as parents or adults. The husbands often became childish, which resulted in conflicts between them and their children, which then had to be resolved by the women. As a result of this the women felt that they had to assume the roles of both parents to their children. The women also expressed feeling that as a result of the extra demands on their time they could not give their children the attention they needed. Some women felt that their children had to "grow up" more quickly and had really missed out by not having a father figure. Examples of statements which best illustrate this subtheme are:

1. It's been hard on the children, especially our oldest daughter, especially when she can outsmart her father.
2. There are fights between the kids and him.
3. Our young son won't bring friends home, it's really hard on him. They used to do so many things together.
4. I couldn't give the kids the attention they needed.
5. I have to be both mom and dad to the kids.

The third subtheme referred to changes within the family as a whole. These changes were described as positive and related to an increased closeness among family members. Examples of statements which best illustrate this subtheme are:

1. Brought family even closer together.
2. We are closer as a family.

As a fourth general theme, many women described changes in their lifestyles. The only positive example of a change in lifestyle was that for one woman the consequences of her husband's brain injury provided the impetus for her to return to school. Negative changes in lifestyle were described in terms of work, social life, finances, and recreation. One important aspect of this theme was the denial by the women of their needs, secondary to their husbands or families. Some women left work to devote themselves to the care of their husbands. Other women returned to work in order to compensate for their husbands' loss of income. Some women described a more restricted social life because their husbands felt uncomfortable in social situations due to decreased cognitive abilities. Some couples also lost friends who were unable to accept the character changes in the husbands. Financial concerns had a decidedly negative impact on the majority of women. Financial worries put an additional strain on an already stressful situation. Decreased financial resources also resulted in lifestyle changes. The changes in the husbands in terms of decreased physical abilities resulted in changes in leisure and recreational activities. It seemed that more organization and planning were required for recreational activities. Examples which best illustrate this theme are:

1. Lost social contact.
2. Significant financial pressure.
3. We just can't get up and go and do things.

A fifth general theme referred to the presence or absence of support. Several women described feeling that they received support from others. This support was described in terms of both emotional support and physical assistance with such things as house and yard work. Examples of statements which illustrate feelings of support are:

1. Family and friends rallied to support us, people were kind to us.

2. All the churches prayed for us.

3. It's helped me appreciate my small town because we've lived here a long time and people stood behind us - there was strong support.

Other women described a lack of support in terms of family, health care professionals, social services, and the government. Some women expressed disappointment in the amount of support provided by their husbands' families. The lack of support from extended families seemed to suggest a lack of acceptance or even denial of the husbands' disabilities. Women expressed that it was often difficult for people, outside of the immediate family, to understand the often dramatic changes which had occurred because their husbands looked the same, that is, there was no visible evidence of disability. Some women expected that physicians or other medical personnel should have been able to provide more information and support and they felt frustrated when this information and support was not forthcoming. Examples of statements which best illustrate this feeling of a lack of support are:

1. Lack of support medically and from social services.

2. I was disappointed in the little support we received for the family from the hospital.

3. I'm frustrated with the government and their lack of financial support/assistance.

Second Open-Ended Question

In relation to the second open-ended question "Please list the ways in which you have dealt with your husband's brain injury", the following general themes were derived. As a first theme, the women described various activities which helped them deal with their husbands' brain injuries. Many women described their work as a form of escape from the stresses and conflicts at home. Some women became more involved in work-related activities so that they would not be around their husbands as much. One woman became involved in volunteer work and one woman returned to school. Examples of statements which best illustrate this aspect of the theme are:

1. I do more things that are work related, for example, conferences, which don't include him and are a form of escape.

2. Becoming involved in volunteer work.

3. I took registered nurses' training as a way of dealing with it.

The women pursued of a wide variety of leisure and recreational activities to help them deal with the consequences of their husbands' brain injuries. Some of these included solitary pursuits such as crafts or reading while others involved activities with family members or friends. Some women increased their activities with others outside of the home to compensate for their decreased levels of activity with their husbands. There seemed to be a process whereby over time women came to recognize and accept the need for self-care. They described that at the time of injury much of their focus was on their husbands, other family members, and adjusting to the often-times dramatic changes in routine. Over time, however, the women recognized the need to take care of themselves. They then acknowledged that they had needs which were not being met within their relationships. These needs would, therefore, have to be met outside of their relationships. Examples of statements which best illustrate this aspect of the theme are:

1. My husband has become a recluse so I've become more outgoing in other areas of my life to compensate.

2. I go skiing with my daughter.

3. I do a lot of reading. It helps keep me sane.

As a second theme the women described various sources of support which helped them to deal with their husbands' brain injuries. One source of support was social support which included both immediate and extended family and friends. One woman experienced support from her husband's co-workers. Many of the women indicated that their children provided a great deal of support. Some women even suggested that they may not have survived the trauma of their husbands' injuries and its' consequences were it not for their children. Examples of statements which best illustrate this aspect of the theme are:

1. I have good neighbors and friends.

2. Kids were and are a tremendous support for me.

3. My husband's company has been ace - drove him to and from the hospital and invite us to company functions.

Several women attended individual, marital, or family counselling as a means of dealing with their husbands' brain injuries. Examples of statements which best illustrate this aspect of the theme are:

1. My husband attends counselling.
2. We're getting family counselling.

Several women attended some type of group program. This type of support occurred through brain injury organizations, hospitals, or private organizations. An example of a statement which illustrates this aspect of the theme is:

1. Belonged to a woman's support group in order to work through my own feelings.

Several women received support in terms of financial resources. Examples of statements which best illustrate this aspect of the theme are:

1. Got funding.
2. I had the financial resources to make a go of things.

As a third theme the women described various actions, thoughts, attitudes, and outlooks which helped them deal with their husbands' brain injuries. There were both positive and negative aspects of this theme. On the positive side, many of the women functioned with a realistic outlook of the situation they were in. For some women there was even a sense of hope and optimism for further improvement or recovery. Whatever form it took, these women seemed to have their husbands' comfort foremost in their minds. Extra work was just done because it had to be done and any additional strain on the women was just accepted. An important aspect of this theme was the strong sense of commitment many of these women had to the relationships with their husbands. Examples of statements which best illustrate this theme are:

1. I have adjusted time schedules, personal and family, in order to accommodate the changes.
2. Moving to a smaller town was helpful.

3. Take one day at a time.
4. Find a solution and go ahead and do it, cope, deal with it.
5. I've had to accept it - that makes it easier.

For other women there was a sense that what they did to deal with the consequences of their husbands' brain injuries, they did without any choice. They did not see themselves as having a choice to make in that the alternative of leaving was not very attractive, so they did what they could. The consequences of leaving the relationship, in terms of loss of stability and security, may have been too great for any serious consideration of such action. There was an air of resignation about some of these women. Predominant among the statements which best illustrate this aspect of the theme was the behavior of ignoring the husband such as:

1. I do what I have to do.
2. Sometimes I just tune him out.
3. I try to ignore a lot of things going on - put them out of my mind.

As a fourth and final theme, some women used their faith or organized religion as a means of dealing with the effects of their husbands' brain injuries. A belief that some Being more powerful than themselves is controlling their lives comforts some persons in times of great distress. The belief that they were being watched over and cared for gave a certain strength to these women, which they felt would be absent otherwise. Examples of statements which best illustrate this theme are:

1. My faith keeps me going.
2. Joined a church organization.
3. I believe in God and I pray.
4. I found the Lord.
5. I get my strength from the Lord.

Quantitative Analyses

Hypotheses

Six variables related to the process of adaptation were investigated including (a) the levels of psychosocial functioning of the injured males as measured by an adaptation of the Portland Adaptability Inventory (PAI) (Lezak, 1987), (b) the levels of subjective burden of the wives as measured by the Subjective Burden Scale (SBS) (McKinlay et al., 1981), (c) the levels of dyadic adjustment of the wives as measured by the Dyadic Adjustment Scale (DAS) (Spanier, 1976), (d) the levels of social support of the wives as measured by the Social Support Inventory (SSI) (McCubbin, et al., 1982), (e) the coping strategies of the wives as measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, et al., 1981), and (f) the well-being of the wives as measured by the Family Member Well-being Index (FWBI) (McCubbin & Patterson, 1982). As all of the self-report measures were completed by the women, it was their perceptions which were investigated.

The hypotheses were tested using a one-tailed test. The correlations between all of the self-report measures are found in Table 4. A diagrammatic representation of the correlations between the self-report measures is found in Figure 2. The results are as follows:

1. The first hypothesis predicted a positive relationship between the husband's level of psychosocial functioning and his wife's level of well-being. This hypothesis was supported by this research in that the correlation between these two measures was .42. (The measures of psychosocial functioning and well-being are both weighted in a negative direction.)

2. The second hypothesis predicted a negative relationship between the wife's level of subjective burden and her level of well-being. This hypothesis was supported by this research in that the correlation between these two measures was .64. (The measure of well-being is weighted in a negative direction.)

3. The third hypothesis predicted a positive relationship between the wife's level of dyadic adjustment and her level of well-being. This hypothesis was supported by this research in that the

Table 4

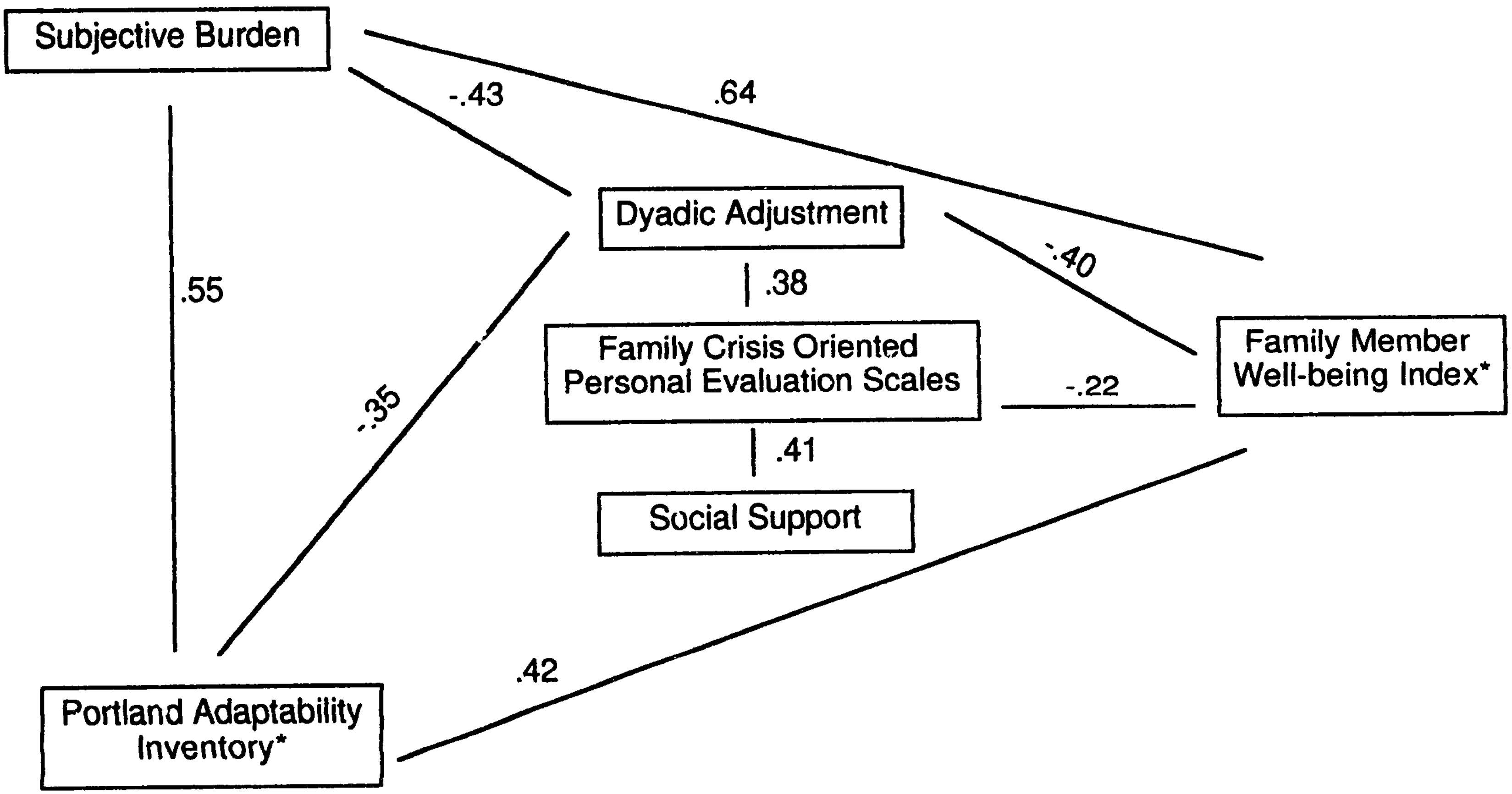
Intercorrelations Between the Portland Adaptability Inventory (PAI), Subjective Burden Scale (SBS), Dyadic Adjustment Scale (DAS), Social Support Inventory (SSI), Family Crisis Oriented Personal Evaluation Scales (F-COPES), and the Family Member Well-being Index (FWBI)

	PAI**	SBS	DAS	SSI	F-COPES
SBS	.55*				
DAS	-.35*	-.43*			
SSI	-.01	-.19	.16		
F-COPES	-.12	-.16	.38*	.41*	
FWBI**	.42*	.64*	-.40*	-.17	-.22*

*p <.05

**measures are weighted in a negative direction

Figure 2. Diagrammatic representation of the intercorrelations between the six self-report measures



* measures are weighted in a negative direction

correlation between these two measures was -.40. (The measure of well-being is weighted in a negative direction.)

4. The fourth hypothesis predicted a positive relationship between the wife's level of social support and her level of well-being. This hypothesis was not supported by this research.

5. The fifth hypothesis predicted a positive relationship between the wife's level of coping and her level of well-being. This hypothesis was supported by this research in that the correlation between these two measures was -.22. (The measure of well-being is weighted in a negative direction.)

Research Questions

Portland Adaptability Inventory (PAI).

A modified version of the PAI (Lezak, 1987) was used to assess the levels of psychosocial functioning of the husbands. The administration of the PAI in this study differed from the original administration developed by Lezak. Lezak used information gathered from the individual with the brain injury, observations made by the examiner, and reports from third persons (such as family members and medical personnel), in order to complete the PAI. The present study used information obtained from the wife of a man with a brain injury during a telephone interview.

Given the difference between the administration of the PAI in this study and the administration by Lezak, it is not appropriate to compare this study's results with reported norms. The following discussion focuses exclusively on the data obtained from the current sample. Percent and frequency data for the PAI are presented in Table 5. The ranges, means, and standard deviations for the subscales and total scale of the PAI are found in Table 6. The minimum score obtainable is 0 and the maximum is 72. The mean PAI total score for the men in this study was, M=19.5 (SD=7.1). This score indicated that the wives of these men reported that their husbands experienced mild levels of difficulty overall in relation to psychosocial functioning. In relation to individual subscales the women reported that their husbands experienced "moderate" levels of difficulty in relation to the Temperament and Emotionality subscale. In terms of individual items on this subscale, the women, as a group, reported that their husbands

Table 5

Percent and Frequency Data for the Portland Adaptability Inventory (n=62)

For each of the indicators circle the most appropriate response regarding husband/partner's present functioning:

	%	(f)	
Irritability/aggression	21	(13)	Socially appropriate/within normal limits.
	22.6	(14)	Mild irritability/verbal aggression.
	35.5	(22)	Moderate irritability/verbal aggression.
	21.0	(13)	Physical aggression or severe verbal aggression.
Anxiety/agitation	8.1	(5)	Socially appropriate/within normal limits.
	22.6	(14)	Mild anxiety/agitation.
	37.1	(23)	Moderate anxiety/agitation.
	32.3	(20)	Severe anxiety/agitation.
Indifference	43.5	(27)	Socially appropriate/within normal limits.
	19.4	(12)	Mild indifference to problems.
	27.4	(17)	Moderate indifference - denies seriousness of problems.
	9.7	(6)	Severe indifference - denies existence of problems.
Depression	6.5	(4)	None.
	32.3	(20)	Mild.
	46.8	(29)	Moderate.
	14.5	(9)	Severe - disruptive for practical purposes.
Delusions/hallucinations	83.9	(52)	None.
	9.7	(6)	Mild.
	6.5	(4)	Moderate.
	0	(0)	Severe - disruptive for practical purposes.

table continues

	%	(f)	
Paranoia	54.8	(34)	None.
	21	(13)	Mild.
	17.7	(11)	Moderate.
	6.5	(4)	Severe - disruptive for practical purposes.
Initiative	29	(18)	Socially appropriate/within normal limits.
	41.9	(26)	Slow to get started; initiates less conversation/activity but insufficient for many practical purposes.
	27.4	(17)	Initiates some conversation/activity but insufficient for many practical purposes.
	1.6	(1)	Initiates no conversation or planned activity.
Significant relationships	14.5	(9)	Unchanged.
	25.8	(16)	Mildly disturbed.
	59.7	(37)	Moderately disturbed.
	0	(0)	No significant relationships.
Residence	96.8	(60)	Single or family residence (no support).
	3.2	(2)	Single or family residence (support).
	0	(0)	Structured living in community.
	0	(0)	Institution.
Social contact	16.1	(10)	No decrease.
	32.3	(20)	Mild decrease.
	46.8	(29)	Moderate decrease.
	4.8	(3)	Total isolation.

table continues

	%	(f)	
Self-care	75.8	(47)	Full self-care.
	16.1	(10)	Partial self-care - mild difficulties.
	8.1	(5)	Partial self-care - moderate difficulties.
	0	(0)	Needs full care.
Work	16.1	(10)	Same work, different work-same level, different or same work-higher level.
	3.2	(2)	Lower level but same general work classification.
	24.2	(15)	Much lower level but same general work classification or sheltered workshop or assumes and maintains regular chore schedule at home.
	56.5	(35)	Does not work.
Leisure activities	11.3	(7)	No loss of self initiated activities.
	43.5	(27)	Mild loss of self initiated activities.
	43.5	(27)	Severe loss of self initiated activities, mostly passive pursuits (watch T.V., drink coffee).
	1.6	(1)	No self initiated activity ("sits and stares," "sleeps a lot").
Driving	62.9	(39)	No change.
	6.5	(4)	Increase in driving infractions and/or minor accidents.
	0	(0)	Suspended automobile license but continues to drive and/or accidents involving damage or injury.
	30.6	(19)	Incapable of driving.

table continues

	%	(f)	
Law violations	90.3	(56)	None
	9.7	(6)	Minor conviction - no time served and no probation.
	0	(0)	Summary conviction or indictable offence - with probation.
	0	(0)	Summary conviction or indictable offence - with time served.
Alcohol use	64.5	(40)	None.
	27.4	(17)	Mild use (social).
	4.8	(3)	Moderate use.
	3.2	(2)	Problem drinking.
Drug use	24.2	(15)	None.
	50	(31)	Mild use.
	17.7	(11)	Moderate use.
	8.1	(5)	Problem drug use.
Social interaction	58.1	(36)	Socially appropriate/within normal limits.
	32.3	(20)	Occasional inappropriate behavior.
	9.7	(6)	Frequent inappropriate behavior (childish, silly, out-of-place).
	0	(0)	Practically complete lack of appropriate behavior.
Walking	67.7	(42)	No detectable impairment or non increase in preinjury impairment.
	19.4	(12)	Walks unaided but with a limp.
	12.9	(8)	Walks with cane, crutches, or walker.
	0	(0)	Cannot walk even with aids.

table continues

	%	(f)	
Use of hands	74.2	(46)	Neither hand impaired or no increase in preinjury impairment.
	11.3	(7)	Only nonpreferred hand impaired.
	9.7	(6)	Only preferred hand impaired.
	4.8	(3)	Impairment of both hands.
Hearing	71.0	(44)	No impairment or no increase in preinjury impairment.
	17.7	(11)	Slight impairment relative to preinjury impairment but within socially useful range.
	11.3	(7)	Lacks reliable or useful social hearing.
	0	(0)	Practically deaf.
Vision	45.2	(28)	No impairment or no increase in preinjury impairment.
	25.8	(16)	Slight impairment relative to preinjury impairment.
	29	(18)	Impairment sufficient to require glasses or change in preinjury prescription or to interfere with ordinary activities.
	0	(0)	Practically blind.
Speech	75.8	(47)	No impairment or no increase in preinjury impairment.
	21	(13)	Mild - easy to understand.
	1.6	(1)	Moderate - difficult for strangers to understand.
	1.6	(1)	Severe - incomprehensible or no speech.
Language	58.1	(36)	No impairment or no increase in preinjury impairment.
	24.2	(15)	Mild - has adequate communication skills for most conversation and practical purposes.
	17.7	(11)	Moderate some communication ability insufficient for many practical purposes.
	0	(0)	Severe - insufficient for practical purposes or absent.

Table 6

Ranges, Means, and Standard Deviations for the Portland Adaptability Inventory (PAI) Subscales and Total Scale

PAI Subscale	Range	Mean	Standard Deviation
Temperament and Emotionality	0-16	8.2	4.0
Activities and Social Behavior	0-17	8.3	3.9
Physical Capabilities	0-9	3.0	2.6
PAI Total Scale	1-35	19.5	7.1

experienced the greatest difficulties with anxiety, depression, and irritability and the least difficulties with delusions/hallucinations and paranoia. In relation to the Activities and Social Behavior subscale, the women reported that their husbands experienced "mild" levels of difficulty. The women reported that their husbands experienced the greatest difficulties in terms of work and significant relationships and the least difficulties in terms of place of residence, law violations, and self-care. With regard to the Physical Capabilities subscale the women reported that their husbands experienced "mild" levels of difficulty. The women reported that their husbands experienced the greatest difficulties with vision and aphasia (language - ability to communicate) and the least difficulties with dysarthria (speech) and hearing.

A significant correlation was found (-.35) between the mens' levels of psychosocial functioning and the levels of dyadic adjustment as reported by the women. As the mens' levels of psychosocial functioning decreased (an increase in the PAI score) the womens' levels of dyadic adjustment decreased (a decrease in the DAS score).

The correlations between the self-report measures and the demographic and injury variables are found in Table 7. The results suggested that as the levels of psychosocial functioning of the husbands increased (a decrease in the PAI score) the number of children living at home increased, employment of the husbands increased, and financial strain and role changes for the women decreased.

Subjective Burden Scale (SBS).

The levels of subjective burden experienced by the women were measured by the SBS (McKinley et al., 1981). Subjective burden was assessed using a simple 7-point scale ranging from (1) I feel no strain or distress as a result of the changes in my husband/partner to (7) I feel severe strain or distress as a result of the changes in my husband/partner. Each subject was asked this question during the telephone interview and then responded to the same question again, in written form, in the package of self-report measures. The correlation between the verbal administration and the written administration of the SBS was .52. Due to the low correlation it was decided to use the average score as being the most valid measure of the subjective burden of

Table 7

Intercorrelations Between the Portland Adaptability Inventory (PAI), Subjective Burden Scale (SBS), Dyadic Adjustment Scale (DAS), Social Support Inventory (SSI), Family Crisis Oriented Personal Evaluation Scales (F-COPES), and Family Member Well-being Index (FWBI), and Selected Demographic and Injury Variables

	PAI	SBS	DAS	SSI	F-COPES	FWBI
Age of the woman	.20	.07	-.07	.04	-.21	.10
Age of the man	.23	.01	-.02	.12	-.26*	.06
Number of years married	.02	-.03	-.01	.16	-.16	-.03
Number of children living at home	-.29*	-.10	-.08	-.08	.06	-.06
Education of woman	-.17	-.02	.12	.15	.02	.03
Education of man	-.20	-.22	.21	.35*	.21	-.25

table continues

	PAI	SBS	DAS	SSI	F-COPES	FWBI
Employment of woman	-.00	-.13	.15	-.18	.22	-.12
Employment of man	.55*	.18	-.06	.12	.06	.25*
Occupation of woman	.08	.14	-.09	.15	-.16	.10
Occupation of man	-.11	-.13	.15	.36*	.19	-.08
Financial Strain	.27*	.37*	-.29*	-.04	.00	.34*
Role change	.40*	.32*	-.20	.08	-.10	.24
Number of months post-injury	.22	.25	-.30*	.03	-.23	.01

* $p < .05$

the women. Although the correlation betwen the two administrations of the SBS was low, the correlation between the womens' subjective burden scores and their well-being scores was significant. The means, standard deviations, frequencies, and percents for this scale are found in Table 8. Overall the women reported "moderate" (SBS score of 3-4) to "high" (SBS score of 5-7) levels of subjective burden, M=4.7 (SD=1.2).

As the husbands' levels of psychosocial functioning decreased (an increase in the PAI scores) the womens' levels of subjective burden increased (an increase in the SBS scores). The correlation between these two measures was .55 (p<.05). There was also a significant correlation (-.43) between the womens' levels of subjective burden and their levels of dyadic adjustment. As the womens' levels of subjective burden increased (an increase in the SBS scores) their levels of dyadic adjustment decreased (a decrease in the DAS scores).

There are very few published norms of the SBS. Brooks et al. (1986) provide data on the SBS for the same group of relatives, of a person who had sustained a severe blunt head injury, over a 5 year period. They report that at 5 years post-injury, 56% of the relatives reported a "high" level of stress and 33% reported a "medium" level of stress. In the present study (an average of 5.1 years post-injury) 46.8% of the women reported a "high" level of stress and 43.5% of the women reported a "medium" level of stress. The two studies were quite comparable in terms of percentage of women who reported a "low" level of stress (SBS scores of 1-2). Brooks et al. (1986) report 10% and the present study reported 9.7%.

The levels of subjective burden were positively correlated with financial strain and role change.

Dyadic Adjustment Scale (DAS).

Relationship adjustment was measured by the DAS (Spanier, 1976). The percent and frequency data for the DAS are found in Table 9. The means and standard deviations for this study's sample and Spanier's (1976) married and divorced samples are found in Table 10. Spanier (1989) suggests that raw scores of less than 100 on the total Dyadic Adjustment Scale can be used as a criterion for identifying poor dyadic adjustment. The data were analyzed,

Table 8

<u>Means, Standard Deviations, Percents, and Frequencies for the Two Administrations of the Subjective Burden Scale</u>

			Response													
			1		2		3		4		5		6		7	
Administration	Mean	Standard Deviation	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
Verbal (Telephone Interview)	4.4	1.5	3.2	(2)	9.7	(6)	12.9	(8)	27.4	(17)	22.6	(14)	14.5	(9)	9.7	(6)
Written (Mail-out Package)	4.9	1.3	1.6	(1)	1.6	(1)	8.1	(5)	24.2	(15)	30.6	(19)	25.8	(16)	8.1	(5)
			Average Response													
			1.5		2.5		3.0		3.5		4.0		4.5		5.0	
			%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
			1.6	(1)	8.1	(5)	3.2	(2)	6.5	(4)	19.4	(12)	14.5	(9)	11.3	(7)
Average (of the 2 administrations)	4.7	1.2														
			5.5		6.0		6.5		7.0							
			%	(f)	%	(f)	%	(f)	%	(f)						
			14.5	(9)	14.5	(9)	3.2	(2)	2.2	(2)						

Table 9

Percent and Frequency Data for the Dyadic Adjustment Scale (n=62)

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list by circling the appropriate number.

		Always Agree		Almost Always Agree		Occasionally Disagree		Frequently Disagree		Almost Always Disagree		Always Disagree	
		%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
1.	Handling family finances	14.5	(9)	27.4	(17)	38.7	(24)	16.1	(10)	3.2	(2)	0	(0)
2.	Matters of recreation	11.3	(7)	37.1	(23)	32.3	(20)	11.3	(7)	8.1	(5)	0	(0)
3.	Religious matters	24.2	(15)	33.9	(21)	22.6	(14)	9.7	(6)	4.8	(3)	4.8	(3)
4.	Demonstration of affection	17.7	(11)	21	(13)	35.5	(22)	19.4	(12)	3.2	(2)	3.2	(2)
5.	Friends	9.7	(6)	40.3	(25)	33.9	(21)	8.1	(5)	8.1	(5)	0	(0)
6.	Sex relations	11.3	(7)	30.6	(19)	25.8	(16)	22.6	(14)	4.8	(3)	4.8	(3)

table continues

		Always Agree		Almost Always Agree		Occasionally Disagree		Frequently Disagree		Almost Always Disagree		Always Disagree	
		%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
7.	Conventionality (correct or proper behavior)	9.7	(6)	16.1	(10)	41.9	(26)	21	(13)	9.7	(6)	1.6	(1)
8.	Philosophy of life	11.3	(7)	27.4	(17)	27.4	(17)	21	(13)	11.3	(7)	1.6	(1)
9.	Dealing with parents or in-laws	9.7	(6)	38.7	(24)	24.2	(15)	12.9	(8)	8.1	(5)	6.5	(4)
10.	Aims, goals, and things believed important	14.5	(9)	30.6	(19)	30.6	(19)	17.7	(11)	4.8	(3)	1.6	(1)
11.	Amount of time spent together	14.5	(9)	37.1	(23)	27.4	(17)	12.9	(8)	6.5	(4)	1.6	(1)
13.	Household tasks	16.1	(10)	22.6	(14)	25.8	(16)	25.8	(16)	3.2	(2)	6.5	(4)
14.	Leisure-time interests and activities	9.7	(6)	27.4	(17)	41.9	(26)	9.7	(6)	6.5	(4)	4.8	(3)
15.	Career decisions	16.1	(10)	41.9	(26)	24.2	(15)	12.9	(8)	1.6	(1)	3.2	(2)

table continues

Please indicate below the best response to each statement by circling the appropriate number.

	All the Time		Most of the Time		More Often Than Not		Occasionally		Rarely		Never	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	(0)	0	(0)	11.3	(7)	32.3	(20)	25.8	(16)	30.6	(19)
17. How often do you or your mate leave the house after a fight?	0	(0)	4.8	(3)	3.8	(3)	22.6	(14)	30.6	(19)	37.1	(23)
18. In general, how often do you think that things between you are your partner are going well?	8.1	(5)	3.7	(23)	32.3	(20)	14.5	(9)	8.1	(5)	0	(0)

table continues

		All the Time		Most of the Time		More Often Than Not		Occasionally		Rarely		Never	
		%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
19.	Do you confide in your mate?	17.7	(11)	40.3	(25)	12.9	(8)	21	(13)	6.5	(4)	1.6	(1)
20.	Do you ever regret that you married (or lived together)?	0	(0)	4.8	(3)	4.8	(3)	30.6	(19)	29.0	(18)	30.6	(19)
21.	How often do you and your partner quarrel?	0	(0)	6.5	(4)	12.9	(8)	50	(31)	29	(18)	1.6	(1)
22.	How often do you and your mate "get on each other's nerves"?	1.6	(1)	9.7	(6)	19.4	(12)	54.8	(34)	12.9	(8)	1.6	(1)

table continues

23. Do you kiss your mate? Please circle the appropriate number.

Every day		Almost every day		Occasionally		Rarely		Never	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
48.4	(30)	21	(13)	21	(13)	6.5	(4)	3.2	(2)

24. Do you and your mate engage in outside interests together? Please circle the appropriate number.

All of them		Most of them		Some of them		Very few of them		None of them	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
9.7	(6)	32.3	(20)	35.5	(22)	16.1	(10)	6.5	(4)

table continues

How often would you say the following occur between you and your mate. Please circle the appropriate number.

		Never		Less than Once a Month		Once or Twice a Month		Once or Twice a Week		Once a Day		More Often	
		%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
25.	Have a stimulating exchange of ideas	6.5	(4)	30.6	(19)	14.5	(9)	29	(18)	11.3	(7)	8.1	(5)
26.	Laugh together	3.2	(2)	8.1	(5)	19.4	(12)	22.6	(14)	30.6	(19)	16.1	(10)
27.	Calmly discuss something	3.2	(2)	14.5	(9)	12.9	(8)	32.3	(20)	25.8	(16)	11.3	(7)
28.	Work together on a project	14.5	(9)	22.6	(14)	19.4	(12)	25.8	(16)	11.3	(7)	6.5	(4)

table continues

These are some things about which couples agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Circle yes or no.)

	Yes		No	
	%	(f)	%	(f)
29. Being too tired for sex	62.5	(39)	37.1	(23)
30. Not showing love	46.8	(29)	53.2	(33)

31. The dots on the following line represent different degrees of happiness in your relationship. The point, "happy," represents the degree of happiness of most relationships. Please circle the dot that best describes the degree of happiness, all things considered, of your relationship.

0		1		2		3		4		5		6	
Extremely unhappy		Fairly unhappy		A little unhappy		Happy		Very happy		Extremely happy		Perfect	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
3.2	(2)	17.7	(11)	35.5	(22)	19.4	(12)	14.5	(9)	8.1	(5)	1.6	(1)

table continues

32. Please circle the number of the following statement that best describes how you feel about the future of your relationship:

A. I want desperately for my relationship to succeed and would go to almost any lengths to see that it does.

%	(f)
24.2	(15)

B. I want very much for my relationship to succeed and will do all that I can to see that it does.

%	(f)
38.7	(24)

C. I want very much for my relationship to succeed and will do my fair share to see that it does.

%	(f)
24.2	(15)

D. It would be nice if my relationship succeeded, and I can't do much more than I am doing now to help it succeed.

%	(f)
11.3	(7)

table continues

E. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

%	(f)
0	(0)

F. My relationship can never succeed, and there is no more that I can do to keep the relationship going.

%	(f)
1.6	(1)

Table 10

Means and Standard Deviations for the Study Sample and the Married and Divorced Normative Samples on the Dyadic Adjustment Scale (DAS) Subscales and Total Scale

	Study Sample (n=62)		Married Normative Sample (n=218)		Divorced Normative Sample (n=94)	
DAS Subscale	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation
Dyadic Consensus	42.1	11.7	51.9	8.5	35.4	11.1
Dyadic Satisfaction	33.1	7.8	40.5	7.2	22.2	10.3
Affectional Expression	7.2	2.9	9.0	2.3	5.1	2.8
Dyadic Cohesion	12.9	4.9	13.4	4.2	8.0	4.9
DAS Total Scale	95.2	24.4	114.8	17.8	70.7	23.8

using t-tests for independent samples, in order to determine whether the women in the study differed from the married and divorced normative groups in terms of dyadic adjustment. The findings indicated that the sample of women in relationships with men who had sustained brain injuries, experienced a lesser degree of dyadic adjustment ($t=6.97$, $p<.05$) than the married normative sample and a greater degree of dyadic adjustment than the divorced normative sample ($t=6.22$, $p<.05$).

A hotelling t^2 test was conducted on the DAS subscales in order to determine whether the study group scores differed from the normative group scores. This analysis is presented in Table 11 and indicated that the women in the study differed from the married normative group on all four subscales. The Dyadic Consensus subscale measures the level of agreement between partners on such matters as money, religion, friends, and time spent together. The women reported the greatest degree of agreement (consensus) with their spouses on matters pertaining to "ways of dealing with parents or in-laws" and the least degree of agreement with their spouses on "career decisions". The Dyadic Satisfaction subscale measures the amount of tension in the relationship and the extent to which the individual has considered ending the relationship. High scores on this subscale suggest satisfaction with the relationship and a commitment to its' continuance. The women reported the greatest tension in their marriages in relation to "getting on each other's nerves" and the least in relation to "do you kiss your mate?". The Dyadic Cohesion subscale measures the common interests and activities shared by the partners. The women reported the greatest "cohesion" with their husbands in relation to "laughing together" and the least "cohesion" with their husbands in relation to "working together on a project". The Affectional Expression subscale measures the womens' satisfaction with the expression of affection and sex in the relationship. The women reported greater satisfaction with the expression of affection than with "sexual relations" in their marital relationships.

As mentioned previously, dyadic adjustment was significantly correlated with both the levels of subjective burden of the wives and the levels of psychosocial functioning of the husbands as

Table 11

Hotelling t^2 Tests for Dyadic Adjustment Scale (DAS) and the Family Crisis Oriented Personal Evaluation Scales (F-COPES) Subscales

	Study Group n=62		Norm Group		t^2	F
	Mean	Standard Deviation	Mean	Standard Deviation		
DAS:						
Dyadic Consensus	42.1	11.7	51.9	8.5	43.3	10.3*
Dyadic Satisfaction	33.1	7.8	40.5	7.2	55.4	13.2*
Dyadic Cohesion	12.9	4.9	13.4	4.2	38.6	9.2*
Affectional Expression	7.2	2.9	9.0	2.3	284.3	67.6*
F-COPES:						
Acquiring Social Support	25.1	7.9	27.8	6.5	7.4	1.4
Reframing	29.7	5.5	30.4	4.9	1.1	0.2
Seeking Spiritual Support	12.2	4.3	16.6	2.9	63.9	11.9*
Mobilizing Family to Acquire and Accept Help	13.2	4.0	12.7	3.3	1.1	0.2
Passive Appraisal	15.4	3.2	8.2	3.1	322.6	60.3*

* $p < .05$

reported by their wives. In addition, there was a significant correlation between the levels of dyadic adjustment and the levels of coping. As dyadic adjustment increased (an increase in the DAS score) the levels of coping increased (an increase in the F-COPES score).

The total dyadic adjustment score was also correlated with financial strain and the number of months post-injury. The results indicated that as dyadic adjustment scores increased (an increase in the DAS score) there was a decrease in financial strain and a decrease in the number of months post-injury.

Social Support Inventory (SSI).

The SSI (McCubbin et al., 1982) measured the degree of social support perceived by the wives as available to them. It assesses five kinds of support and 12 sources of support. The kinds of support are emotional, esteem, network, appraisal, and altruistic. The sources of support include spouse, children, relatives, friends, co-workers, community groups, church, spiritual faith, professionals and service providers, special groups (designed to help with specific problems or responsibilities), books and television, and other. The scale yields a support score for each of the five kinds of support, the 12 sources of support, and the total support score. The percent and frequency data for the SSI are found in Table 12. The ranges, means, and standard deviations for the SSI subscales and total scale are presented in Table 13. The minimum score obtainable for each kind of support is 0 and the maximum is 24. The minimum score obtainable for each source of support is 0 and the maximum is 10. The minimum SSI total score obtainable is 0 and the maximum is 120.

Unfortunately, very limited normative data on this instrument are available from the authors. In view of this lack of available normative data, the discussion here focuses exclusively on the data obtained from the current sample. The mean SSI total score for the wives was, M=45.0 (SD=15.9). This score indicated that, as a group, these women experienced a moderate amount of social support overall. In terms of the five kinds of support, the women perceived the highest degree of support in terms of altruistic support and the lowest degree of support in terms of

Table 12

Percent and Frequency Data for the Social Support Inventory

Please read each statement and then indicate how much support you receive from each of the sources listed by circling the appropriate response:

	No		Yes		Yes a lot	
1. I have a feeling of being loved or cared about from:	%	(f)	%	(f)	%	(f)
My spouse or partner	11.3	(7)	38.7	(24)	50	(31)
My children	3.2	(2)	33.9	(21)	62.9	(39)
Other relatives	4.8	(3)	56.5	(35)	38.7	(24)
Close friends	12.9	(8)	67.7	(42)	19.4	(12)
Co-workers	48.4	(30)	43.5	(27)	8.1	(5)
Church/Synagogue	56.5	(35)	33.9	(21)	9.7	(6)
My spiritual faith	25.8	(16)	45.2	(28)	29	(18)
Community or neighborhood groups	66.1	(41)	27.4	(17)	6.5	(4)
Professionals or Service Providers	43.5	(27)	50	(31)	6.5	(4)
Special groups I belong to	77.4	(48)	16.1	(10)	6.5	(4)
Reading certain books or watching T.V.	56.5	(35)	33.9	(21)	9.7	(6)
Other	0	(0)	0	(0)	0	(0)

table continues

	No		Yes		Yes a lot	
2. I feel I am valued or respected for who I am and what I can do by:	%	(f)	%	(f)	%	(f)
My spouse or partner	16.1	(10)	35.5	(22)	48.4	(30)
My children	3.2	(2)	37.1	(23)	59.7	(37)
Other relatives	4.8	(3)	61.3	(38)	33.9	(21)
Close friends	11.3	(7)	67.7	(42)	21	(13)
Co-workers	37.1	(23)	53.2	(33)	9.7	(6)
Church/Synagogue	58.1	(36)	33.9	(21)	8.1	(5)
My spiritual faith	27.4	(17)	53.2	(33)	19.4	(12)
Community or neighborhood groups	61.3	(38)	35.5	(22)	3.2	(2)
Professionals or Service Providers	46.8	(29)	45.2	(28)	8.1	(5)
Special groups I belong to	71	(44)	24.2	(15)	4.8	(3)
Reading certain books or watching T.V.	56.5	(35)	38.7	(24)	4.8	(3)
Other	0	(0)	0	(0)	0	(0)
3. I have a sense of trust or security from the "give-and-take" of being involved with:	%	(f)	%	(f)	%	(f)
My spouse or partner	22.6	(14)	40.3	(25)	37.1	(23)
My children	4.8	(3)	46.8	(29)	48.4	(30)
Other relatives	11.3	(7)	67.7	(42)	21	(13)
Close friends	12.9	(8)	67.7	(42)	19.4	(12)
Co-workers	43.5	(27)	46.8	(29)	9.7	(6)
Church/Synagogue	56.5	(35)	45.5	(22)	8.1	(5)

table continues

	No		Yes		Yes a lot	
	%	(f)	%	(f)	%	(f)
My spiritual faith	16.1	(10)	74.2	(46)	9.7	(6)
Community or neighborhood groups	61.3	(38)	35.5	(22)	3.2	(2)
Professionals or Service Providers	48.4	(30)	46.8	(29)	4.8	(3)
Special groups I belong to	72.6	(45)	24.2	(15)	3.2	(2)
Reading certain books or watching T.V.	40.3	(25)	56.5	(35)	3.2	(2)
Other	0	(0)	0	(0)	0	(0)
4. When I need to talk or think about how I'm doing with my life, I feel understood and get help from:	%	(f)	%	(f)	%	(f)
My spouse or partner	37.1	(23)	38.7	(24)	24.2	(15)
My children	29	(18)	41.9	(26)	29	(18)
Other relatives	29	(18)	59.7	(37)	11.3	(7)
Close friends	24.2	(15)	59.7	(37)	16.1	(10)
Co-workers	66.1	(41)	27.4	(17)	6.5	(4)
Church/Synagogue	64.5	(40)	27.4	(17)	8.1	(5)
My spiritual faith	24.2	(15)	51.6	(32)	24.2	(15)
Community or neighborhood groups	77.4	(48)	21	(13)	1.6	(1)
Professionals or Service Providers	59.7	(37)	32.3	(20)	8.1	(5)
Special groups I belong to	80.6	(50)	16.1	(10)	3.2	(2)
Reading certain books or watching T.V.	43.5	(27)	48.4	(30)	8.1	(5)
Other	0	(0)	0	(0)	0	(0)

table continues

	No		Yes		Yes a lot	
5. I feel good about myself when I am able to do things for and help:	%	(f)	%	(f)	%	(f)
My spouse or partner	3.2	(2)	38.7	(24)	58.1	(36)
My children	3.2	(2)	33.9	(231)	62.9	(39)
Other relatives	3.2	(2)	59.7	(37)	37.1	(23)
Close friends	8.1	(5)	59.7	(37)	32.3	(20)
Co-workers	35.5	(22)	51.6	(32)	12.9	(8)
Church/Synagogue	46.8	(29)	33.9	(21)	19.4	(12)
My spiritual faith	11.3	(7)	69.4	(43)	19.4	(12)
Community or neighborhood groups	41.9	(26)	48.4	(30)	9.7	(6)
Professionals or Service Providers	41.9	(26)	51.6	(32)	6.5	(4)
Special groups I belong to	56.5	(35)	37.1	(23)	6.5	(4)
Reading certain books or watching T.V.	62.9	(39)	35.5	(22)	1.61	(1)
Other	0	(0)	0	(0)	0	(0)

Table 13

Ranges, Means, and Standard Deviations for the Social Support Inventory Subscales and Total Scale

SSI Subscale	Range	Mean	Standard Deviation
Emotional Support	2-18	9.4	3.5
Esteem Support	3-18	9.3	3.3
Network Support	2-18	8.8	3.6
Appraisal Support	0-17	7.1	3.5
Altruistic Support	2-20	10.5	3.6
Spouse or partner	0-10	6.3	3.0
Children	0-10	7.2	2.5
Other relatives	0-10	5.9	2.2
Close friends	0-10	5.4	2.6
Coworkers	0-10	3.2	2.9
Church/Synagogue	0-10	2.7	3.1
Spiritual Faith	0-10	5.0	2.6
Community or Neighborhood Groups	0-10	2.2	2.5
Professionals or Service providers	0-10	2.9	2.7
Special groups	0-10	1.7	2.5
Reading or T.V.	0-10	2.7	2.3
Other	0	0.0	0.0
SSI Total Scale	11-85	45.0	15.9

appraisal support. Altruistic support measured how good these women felt about themselves when they were able to do things for and help various people in their support systems. Appraisal support measured whom these women felt understood by and got help from when they needed to talk about how they were doing with their lives. In relation to sources of support, the women perceived the highest degree of support from their children. It is interesting to note that even though these womens' husbands had sustained brain injuries these women still perceived a relatively high degree of support from their husbands, second only to the support they perceived from their children. Overall, these women reported that they obtained moderate levels of support from their immediate and extended families and friends (children, spouses, other relatives, and close friends). In addition they perceived a somewhat less but still moderate degree of support from their spiritual faith. As would be expected, they perceived less support from other sources including co-workers, professionals or service providers, church or synagogue groups, reading books or watching T.V., and community or neighborhood groups. Overall, these women perceived the lowest degree of support from special groups (designed to help with specific difficulties or responsibilities) that they belonged to.

There was a significant correlation between the womens' levels of social support and their levels of coping. As the womens' levels of social support increased (an increase in the SSI score) their levels of coping increased (an increase in the F-COPES score).

Interestingly, the levels of social support were positively correlated with the levels of education and the occupational status of the husbands. The results suggested that as the husbands' levels of education and occupational status increased the womens' levels of social support increased.

Family Crisis Oriented Personal Evaluation Scales (F-COPES).

The F-COPES (McCubbin et al., 1981) was used to identify the problem-solving and behavioral strategies used by women married to men with brain injuries. The percent and frequency data for the F-COPES are found in Table 14. The means and standard deviations for the study sample and the normative sample are presented in Table 15. The minimum score

Table 14

Percent and Frequency Data for the Family Crisis Oriented Personal Evaluation Scales (n=62)

First, read the list of "response choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes *your response very well, then circle the number 5 indicating that you strongly agree*; *if the statement does not describe your response at all*, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2,3, or 4 to indicate how much you agree or disagree with the statement about your response.

When we face problems or difficulties in our family we respond by:

	Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
1. Sharing our difficulties with relatives	25.8	(1)	21.0	(13)	17.7	(11)	21.0	(13)	14.5	(9)

table continues

		Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
		%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
2.	Seeking encouragement and support from friends	16.1	(10)	11.3	(7)	16.1	(10)	41.9	(26)	14.5	(9)
3.	Knowing we have the power to solve major problems	11.3	(7)	11.3	(7)	8.1	(5)	33.9	(21)	35.5	(22)
4.	*Seeking information and advice from persons in* other families who have faced the same or similar problems.	24.2	(15)	9.7	(6)	16.1	(10)	33.9	(21)	16.1	(10)
5.	Seeking advice from relatives (grandparents, etc.)	25.8	(16)	19.4	(12)	22.6	(14)	29.0	(18)	3.2	(2)

table continues

	Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
6. Seeking assistance from community agencies and programs designed to help families in our situation	19.4	(12)	12.9	(8)	21.0	(13)	30.6	(19)	16.1	(10)
7. Knowing that we have the strength within our own family to solve our problems.	4.8	(3)	12.9	(8)	19.4	(12)	35.5	(22)	27.4	(17)
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	25.8	(16)	17.7	(11)	24.2	(15)	25.8	(16)	6.5	(4)
9. Seeking information and advice from the family doctor	8.1	(5)	6.5	(4)	11.3	(7)	40.3	(25)	33.9	(21)
10. Asking neighbors for favors and assistance	35.5	(22)	12.9	(8)	22.6	(14)	25.8	(16)	3.2	(2)

table continues

	Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
11. Facing the problems "head on" and trying to get solution right away	8.1	(5)	11.3	(7)	19.4	(12)	35.5	(22)	25.8	(16)
12. Watching television	43.5	(27)	14.5	(9)	19.4	(12)	14.5	(9)	8.1	(5)
13. Showing that we are strong	6.5	(4)	11.3	(7)	32.3	(20)	30.6	(19)	19.4	(12)
14. Attending church services	22.6	(14)	12.9	(8)	30.6	(19)	19.4	(12)	14.5	(9)
15. Accepting stressful events as a fact of life	3.2	(2)	6.5	(4)	12.9	(8)	53.2	(33)	24.2	(15)
16. Sharing concerns with close friends	11.3	(7)	8.1	(5)	17.7	(11)	48.4	(30)	14.5	(9)
17. Knowing luck plays a big part in how well we are able to solve family problems	46.8	(29)	19.4	(12)	25.8	(16)	8.1	(5)	0	(0)
18. Accepting that difficulties occur unexpectedly	0	(0)	4.8	(3)	11.3	(7)	45.2	(28)	38.7	(24)

table continues

	Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
19. Doing things with relatives (get-togethers, dinners, etc.)	9.7	(6)	22.6	(14)	19.4	(12)	32.3	(20)	16.1	(10)
20. Seeking professional counseling and help for family difficulties	12.9	(8)	21	(13)	16.1	(10)	33.9	(21)	16.1	(10)
21. Believing we can handle our own problems	6.5	(4)	17.7	(11)	21	(13)	37.1	(23)	17.7	(11)
22. Participating in church activities	27.4	(17)	9.7	(6)	35.5	(22)	16.1	(10)	11.3	(7)
23. Defining the family problem in a more positive way so that we do not become too discouraged	3.2	(2)	6.5	(4)	27.4	(17)	38.7	(24)	24.2	(15)
24. Asking relatives how they feel about problems we face	30.6	(19)	21	(13)	29	(18)	16.1	(10)	3.2	(2)

table continues

	Strongly Disagree		Moderately Disagree		Neither Agree Nor Disagree		Moderately Agree		Strongly Agree	
	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
25. Feeling that no matter what we do to prepare, we will have difficulty handling problems.	24.2	(15)	21	(13)	32.3	(20)	19.4	(12)	3.2	(2)
26. Seeking advice from a minister	32.3	(2)	17.7	(11)	32.3	(20)	9.7	(6)	8.1	(5)
27. Believing if we wait long enough, the problem will go away	53.2	(33)	24.2	(15)	14.5	(9)	8.1	(5)	0	(0)
28. Sharing problems with neighbors	43.5	(27)	16.1	(10)	27.4	(17)	12.9	(8)	0	(0)
29. Having faith in God	9.7	(6)	0	(0)	17.7	(11)	11.3	(7)	61.3	(38)

Table 15

Means and Standard Deviations for the Study Sample and the Normative Sample on the Family Crisis Oriented Personal Evaluation Scales (F-COPES) Subscales and Total Scale

	Study Sample (n=62)		Normative Sample (n=77)	
F-COPES Subscale	Mean	Standard Deviation	Mean	Standard Deviation
Acquiring Social Support	25.1	7.9	27.8	6.5
Reframing	29.7	5.5	30.4	4.9
Seeking Spiritual Support	12.2	4.3	16.6	2.9
Mobilizing Family to Acquire and Accept Help	13.2	4.0	12.7	3.3
Passive Appraisal	15.4	3.2	8.2	3.1
F-COPES Total Scale	95.6	15.9	95.6	13.2

obtainable on the total scale is 29 and the maximum is 145. The average coping score for the study sample was, M=95.6 (SD=15.9) which did not differ statistically from the normative sample mean of M=95.6 (SD=13.2). This finding indicated that women married to men who had sustained brain injuries did not differ statistically from the normative sample in terms of coping strategies.

The data were further analyzed using a hotelling t^2 statistic in order to determine whether the subscale scores differed between the study group and the normative group. The results are presented in Table 11 and indicated that the women in the study differed significantly from the normative group on two of the five subscales, Seeking Spiritual Support and Passive Appraisal. The Seeking Spiritual Support subscale assesses the ability to acquire spiritual support. The women in the study reported less use of "seeking spiritual support" than the normative group ($p<.05$). The coping strategy the women reported using most frequently was "having faith in God". The coping strategy they used least was "seeking advice from a minister". The Passive Appraisal subscale measures inactive or passive behaviors a woman might employ, such as avoidance responses, based on a lack of confidence in her ability to alter the outcome of a situation. The women in the study reported more use of "passive appraisal" as a coping strategy than the normative group ($p<.05$). The coping strategy that these women reported using most frequently was "watching T. V.". The coping strategy they used least was "believing if we wait long enough, the problem will go away". No differences were found between the study and normative groups on the other three subscales, Acquiring Social Support, Reframing, and Mobilizing Family to Acquire and Accept Help. The Acquiring Social Support subscale measures the ability to actively engage in acquiring support from relatives, friends, neighbors, and extended family. The women, as a group reported that the coping strategy they used the most, in terms of this subscale, was "sharing concerns with close friends". The coping strategy they used the least was "sharing problems with neighbors". The Reframing subscale measures the ability to redefine stressful events in order to make them more manageable. The women, as a group reported that the most highly used coping strategy, in relation to this subscale, was "accepting that difficulties occur unexpectedly". The coping strategy they used the least was "believing we can handle our own problems". The Mobilizing Family to Acquire and Accept Help subscale measures the ability to seek out community resources and accept help from others. The women as a group sought information and advice most often from their family doctors. They relied least on information and advice from other families who had faced the same or similar problems.

As mentioned previously the levels of coping were significantly correlated with the levels of social support and dyadic adjustment. The only demographic variable that was significantly correlated with the F-COPES score was the age of the husband. The results suggested that as the ages of the husbands increased the coping scores of the wives decreased.

Family Member Well-being Index (FWBI).

The FWBI (McCubbin & Patterson, 1982) was used to measure the "adaptation" of the women. The percent and frequency data for the FWBI are found in Table 16. The minimum score obtainable on this inventory is 0 and the maximum is 80. The higher the score, the less the well-being. Overall, the women in this study reported a "moderate" level of well-being M=42.7 (SD=14.4).

With respect to individual items on the FWBI, the women, as a group, obtained their highest scores (indicative of problems) in relation to "concern with the health of another family member" and "tension". They obtained their lowest scores (indicative of well-being) in relation to "being afraid" and "concern about their own health".

The data were analyzed, using a t-test for independent samples, in order to determine whether the women in the study differed from the normative group in terms of "well-being". The total FWBI score for the study sample, M=42.7 (SD=14.4) differed statistically from that of the normative sample, M=52.1 (SD=13.7). Surprisingly, this finding indicated that the sample of women in relationships with men who had sustained brain injuries reported a higher degree of well-being (t=18.88, p<.05) than the normative sample.

The correlations between the other self-report measures and the FWBI were discussed at the beginning of this section. In relation to the demographic variables, the FWBI total scores were

Table 16

Percent and Frequency Data for the Family Member Well-being Index (n=62)

For each of the eight statements below, please note that the words at each end of the 0 to 10 scale describe opposite feelings. Please fill in the response along the bar which seems closest to how you have generally felt during the past month.

1. How concerned or worried about your health have you been? (During the past month)

Not CONCERNED at all																					Very CONCERNED
0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
16.1	(10)	3.2	(2)	6.5	(4)	4.8	(3)	8.1	(5)	11.3	(7)	9.7	(6)	4.8	(3)	17.7	(11)	4.8	(3)	12.9	(8)

table continues

2. How relaxed or tense have you been? (During the past month)

Very RELAXED

Very TENSE

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
0	(0)	1.6	(1)	4.8	(3)	6.5	(4)	4.8	(3)	17.7	(11)	6.5	(4)	16.1	(10)	19.4	(12)	8.1	(5)	14.5	(9)

3. How much energy, pep, vitality have you felt? (During the past month)

No energy at all

LISTLESS

Very Energetic

DYNAMIC

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
0	(0)	3.2	(2)	9.7	(6)	16.1	(10)	9.7	(6)	30.6	(19)	9.7	(6)	9.7	(6)	8.1	(5)	0	(0)	3.2	(2)

table continues

4. How depressed or cheerful have you been? (During the past month)

Very DEPRESSED | Very CHEERFUL

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
1.6	(1)	6.5	(4)	4.8	(3)	6.5	(4)	14.5	(9)	21	(13)	11.3	(7)	16.1	(10)	12.9	(8)	1.6	(1)	3.2	(2)

5. How afraid have you been? (During the past month)

Not AFRAID | Very AFRAID

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
16.1	(10)	12.9	(8)	6.5	(4)	8.1	(5)	4.8	(3)	17.7	(11)	12.9	(8)	3.2	(2)	9.7	(6)	3.2	(2)	4.8	(3)

table continues

6. How angry have you been? (During the past month)

Not ANGRY at all — Very ANGRY

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
8.1	(5)	11.3	(7)	17.7	(11)	1.6	(1)	11.3	(7)	11.3	(7)	14.5	(9)	6.5	(4)	12.9	(8)	1.6	(1)	3.2	(2)

7. How sad have you been? (During the past month)

Not SAD at all — Very SAD

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
6.5	(4)	8.1	(5)	6.5	(4)	16.5	(4)	9.7	(6)	21	(13)	6.5	(4)	12.9	(8)	12.9	(8)	3.2	(2)	6.5	(4)

table continues

8. How concerned or worried about the health of another family member have you been? (During the past month)

Not CONCERNED at all

Very CONCERNED

0		1		2		3		4		5		6		7		8		9		10	
%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)	%	(f)
3.2	(2)	3.2	(2)	0	(0)	3.2	(2)	3.2	(2)	11.3	(7)	6.5	(4)	11.3	(7)	17.7	(11)	8.1	(5)	32.3	(20)

correlated with the levels of education and employment of the husbands and the levels of financial strain as perceived by the wives. As the womens' levels of well-being decreased (an increase in the FWBI scores), the husbands' levels of education and employment decreased and the levels of financial strain as perceived by the women increased.

The telephone interview data were analyzed, using a t-test for independent samples, to determine whether there were any differences between the Portland Adaptability Inventory (PAI) and the Subjective Burden Scale (SBS) scores (information collected during the telephone interview) of those women who completed the self-report measures (N=62) as compared to those women who did not complete the self-report measures (N=14). The sample of women who completed the self-report measures yielded a PAI score of M=19.5 (SD=7.1) compared to M=19.4 (SD=12.3) for those women who did not complete the self-report measures. This finding indicated that there was no significant difference (t=.07, p>.05) between these two groups on their PAI scores. The sample of women who completed the self-report measures yielded a SBS score of M=4.4 (SD=1.5) compared to M=4.0 (SD=1.4) for those women who did not complete the self-report measures. This finding indicated that there was no significant difference (t=.86, p>.05) between these two groups on their SBS scores.

Analyses were conducted to determine whether the levels of psychosocial functioning of the men differed depending on the type of brain injury. T-tests were used to compare the two groups, traumatic brain injuries (N=44) and "other types" of brain injuries (N=18) on each of the measures. The results are found in Table 17. The traumatic brain injuries group scored significantly higher than the "other types" of brain injuries group on the Temperament and Emotionality subscale of the Portland Adaptability Inventory (PAI). This finding suggested that individuals who sustained traumatic brain injuries experienced greater difficulties with changes in temperament and emotionality than those individuals who sustained "other types" of brain injuries. The "other types" of brain injuries group scored higher than the traumatic brain injuries group on the Family Crisis Oriented Personal Evaluation Scales (F-COPES) total scale and two subscales including Acquiring Social Support and Seeking Spiritual Support. The "other types"

Table 17

T-tests for the Portland Adaptability Inventory (PAI), Subjective Burden Scale (SBS), Dyadic Adjustment Scale (DAS), Social Support Inventory (SSI), Family Crisis Oriented Personal Evaluation Scales (F-COPES), and the Family Member Well-being Index (FWBI) (Total Scale and Subscales) (Traumatic Brain Injury versus Other Types of Brain Injury)

Scale/Subscale	Traumatic Brain Injury		Other Types of Brain Injury		t	p
	Mean	Standard Deviation	Mean	Standard Deviation		
PAI						
Total Scale	19.8	7.8	18.8	5.2	.49	.63
Temperament and Emotionality	8.9	3.8	6.5	3.8	2.27	.03*
Activities and Social Behavior	8.2	4.2	8.5	3.2	-.29	.77
Physical Capabilities	2.7	2.6	3.8	2.5	-1.58	.11
SBS						
Total Scale	4.8	1.2	4.3	1.1	1.41	.16

table continues

Scale/Subscale	Traumatic Brain Injury		Other Types of Brain Injury		t	p
	Mean	Standard Deviation	Mean	Standard Deviation		
DAS						
Total Scale	93.0	25.9	100.8	19.7	-1.15	.26
Dyadic Consensus	41.3	12.5	44.1	9.8	-.84	.41
Dyadic Satisfaction	32.1	8.1	35.6	6.5	-1.59	.12
Dyadic Cohesion	12.8	5.3	13.1	3.6	-.21	.84
Affectional Expression	6.8	2.9	8.1	2.8	-1.64	.11
F-COPES						
Total Scale	92.5	15.3	103.3	15.1	-2.54	.01*
Acquiring Social Support	23.6	7.1	28.6	8.9	-2.34	.02*
Reframing	29.6	5.8	29.9	4.8	-0.21	.84
Seeking Spiritual Support	11.3	4.5	14.4	3.0	-2.65	.01*
Mobilizing Family to Acquire and Accept Help	12.6	4.1	14.8	3.5	-1.98	.05
Passive Appraisal	15.3	3.2	15.6	3.1	-0.30	.76

table continues

Scale/Subscale	Traumatic Brain Injury		Other Types of Brain Injury		t	p
	Mean	Standard Deviation	Mean	Standard Deviation		
SSI						
Total Scale	41.8	13.4	52.9	19.0	-2.63	.01*
Emotional Support	8.7	2.9	11.1	4.3	-2.12	.04*
Esteem Support	8.5	2.8	11.1	3.8	-2.88	.01*
Network Support	8.1	3.2	10.3	4.1	-2.26	.03*
Appraisal Support	6.5	3.2	8.4	4.1	-2.04	.05*
Altruistic Support	9.9	3.2	12.1	4.3	-2.19	.03*
Spouse	6.2	3.1	6.6	2.7	-0.47	.64
Children	7.3	2.5	7.1	2.6	0.27	.79
Other relatives	5.8	2.1	6.2	2.6	-0.76	.45
Close friends	5.0	2.5	6.3	3.1	-1.75	.09
Co-workers	2.5	2.3	4.7	3.5	-2.46	.02*
Church/Synagogue groups	2.2	2.6	3.9	3.9	-1.67	.11
Spiritual faith	4.6	2.6	5.9	2.4	-1.95	.06

table continues

Scale/Subscale	Traumatic Brain Injury		Other Types of Brain Injury		t	p
	Mean	Standard Deviation	Mean	Standard Deviation		
Community of Neighborhood						
groups	1[illegible]	2.2	3.0	3.0	-1.71	.09
Professionals or Service						
Providers	2.4	2.5	4.2	2.8	-2.42	.02*
Special groups	1.5	2.5	2.1	2.7	-0.89	.38
Reading books or watching T.V.	2.5	2.1	3.0	2.9	-0.69	.49
<u>FWBI</u>						
Total Scale	42.4	12.8	43.4	18.1	-0.24	.81

* $p < .05$

of brain injuries group also scored higher than the traumatic brain injuries group on the Social Support Inventory (SSI) in relation to the total scale, all five kinds of support, and two sources of support (co-workers and professionals). These findings suggested that women married to men who had sustained "other types" of brain injuries tended to use more coping strategies and perceived greater levels of social support. No differences were found between these groups on the Portand Adaptability Inventory total test, the Dyadic Adjustment Scale, or the Family Member Well-being Index. There were no differences between the groups, therefore, in terms of the overall psychosocial functioning of the husbands, the levels of marital adjustment of the wives, or the well-being of the wives. A significant correlation was found between the age of the husband and the type of brain injury. The "other types" of brain injuries group was correlated with an increase in the ages of the husbands.

The reliability of the various measures was investigated. The overall Chronbach's alpha was .75 for the Portland Adaptability Inventory (PAI), .96 for the Dyadic Adjustment Scale (DAS), .93 for the Social Support Inventory (SSI), .86 for the Family Crisis Oriented Personal Evaluation Scales (F-COPES), and .82 for the Family Member Well-being Index (FWBI). These estimates of reliability are all in line with those reported in the literature. On the subtests, the reliabilities ranged from .59 to .94. These results indicated that the scales had sufficiently high internal consistency to justify their use.

CHAPTER 5 - DISCUSSION

Introduction

The purpose of this study was to investigate the process of adaptation of women following their husbands' brain injuries. This was done by the use of two open-ended questions and the investigation of the relationships among six variables related to the process of adaptation. The six variables included the husbands' levels of psychosocial functioning and their wives' levels of subjective burden, dyadic adjustment, social support, coping, and well-being In the following chapter the results of the study are discussed and placed within the context of the literature presented.

Resiliency Model

The results of this study appear to provide some support for the Resiliency Model (McCubbin & McCubbin, 1991). There is evidence that a brain injury sustained by a husband creates a crisis for his wife. The results suggest that a woman experiences a "pile-up of demands" following the crisis of a husband's brain injury. There is evidence that marital adjustment is a mediating factor between the "pile-up of demands" and the level of "adaptation" as suggested by Lavee, McCubbin, and Olson (1987). There is also evidence that those women who use more coping strategies have higher levels of "adaptation". The one aspect of the Resiliency Model which is not supported by this research is the role of social support in augmenting a family's strengths. There is no correlation between the scores on the Social Support Inventory (McCubbin, Patterson, Rossman, & Cooke, 1982) and the scores on either the Dyadic Adjustment Scale (Spanier, 1976) or the Family Member Well-being Index (McCubbin & Patterson, 1982). This finding is, however, contradicted by the findings of the qualitative analyses. One of the major themes derived from the responses to a question as to the ways in which these women dealt with the effects of their husbands' brain injuries is support. Perhaps the relationship between social support and well-being is a nonlinear relationship.

Stress

It was predicted that those women who reported the highest levels of "stress" would report the lowest levels of "adaptation". The findings indicate a significant correlation between the first measure of "stress" in the women, their indication of the levels of psychosocial functioning of their husbands, and the measure of their "adaptation", their levels of well-being. As the husbands' levels of psychosocial functioning decrease, the wives' levels of well-being decrease. The findings also indicate a significant relationship between the second measure of "stress" in the women, their levels of subjective burden, and their levels of well-being. As the levels of subjective burden increase the levels of well-being decrease. The correlation between subjective burden and well-being is, in fact, the strongest relationship found in this study. These findings are consistent with those researchers who have described the negative effects for the wives or relatives of individuals with brain injuries (Brooks et al., 1986; Brooks & McKinlay, 1983; Lezak, 1988; Liss & Willer, 1990; Livingston et al., 1985; McKinlay et al., 1981; Thomsen, 1987; Willer et al., 1991). The findings of the present study also indicate a significant relationship between the two measures of "stress", the levels of psychosocial functioning of the husbands and the levels of subjective burden experienced by the wives. Even though these women report that their husbands experience only mild difficulties overall in terms of psychosocial functioning, these women report "moderate" to "high" levels of subjective burden. This finding supports the findings of several researchers who suggest that even mild or moderate levels of brain injury can have negative consequences for family members (Alves, 1989; Binder, 1986; O'Shaughenssy et al., 1984; Rimel et al., 1981; Stuss et al., 1985). The levels of subjective burden reported by the wives of men with brain injuries is quite comparable with the findings of Brooks et al. (1986) who used the SBS with relatives of men who had sustained severe brain injuries. The percentage of women in the present study who report a "high" level of burden is somewhat less than the comparison group while the percentage of women who report a "medium" level of burden is somewhat higher. The range of "years post- injury" in the present study (1 to 21.5 years) is much greater than that in the comparison group (5 years) and may account for the difference in results between the two studies.

In terms of the psychosocial functioning of their husbands, the women report that their greatest difficulties are experienced in relation to changes in the temperaments and personalities of their husbands (specifically decreased tolerance for frustration and increased anger) as opposed to changes in activities and social behaviors or changes in physical capabilities. This finding is consistent with that of Brooks and McKinlay (1983) who found that the association between the relatives' burden and changes in the individuals' (with brain injuries) personalities is greater than that between burden and physical changes. This finding is also consistent with that of Willer et al. (1991) who found that able-bodied wives identify personality changes in their husbands (with brain injuries) as their greatest problem. In terms of the qualitative analyses one of the major themes to emerge is "changes in the husband". These changes are mostly considered to be negative and include changes in personality, emotional expression, cognition, and physical functioning. Three other areas of change reported by these women, which are not addressed by the Portland Adaptability Inventory, include difficulties with memory, concentration, and balance.

In addition to the stress experienced by the women in relation to the changes in their husbands (objective burden type 2 as measured by the PAI), other related "burdens" include financial strain and role changes for the women (objective burden type 1 as measured by the telephone interview questions). In terms of the qualitative analyses two additional themes in relation to the effects of the brain injuries are "changes within and for the women" and "changes in lifestyle". The first theme includes statements about increased stress and an increase in negative feelings in relation to the changed circumstances for the women following their husbands' brain injuries. Many women describe significant role changes in terms of their responsibilities in the home and in their marital relationships. The changes in lifestyle relate primarily to finances, social life, and recreation and tend to have a negative effect on the women. There is a correlation between both measures of stress (psychosocial functioning and subjective burden) and dyadic adjustment, role change, and financial strain. These findings are consistent with those of Willer et al. (1991) who found that role performance changes and a reduction of income are primary problems for able-bodied wives of individuals with brain injuries.

Many women describe the effects of brain injuries in terms of changes in both their and their husbands' relationships with their children. Many women express concerns regarding the effects of these changes on their children. They express particular concern regarding their need to take over the parenting roles of their husbands and the childish and often jealous behavior [illegible]ssed by their husbands in relation to their children. This finding is consistent with that of Willer et al. (1991) who also found that women express concerns regarding the effects on their children of having fathers with brain injuries. Interestingly, the levels of psychosocial functioning of the husbands are significantly correlated with the number of children living at home. As the number of children in the home increases the levels of psychosocial functioning of the men increase (an decrease in the PAI score) . This finding would suggest that in some families, the greater the number of children in the home, the greater the psychosocial functioning of the injured husband.

It is interesting to note that the correlation between the levels of subjective burden of the women and the number of months post-injury is approaching significance, r=.25, p=.050. This finding would suggest that the longer the time since the brain injuries, the greater the sense of burden reported by the women. This result is consistent with the findings of Brooks et al. (1986, 1987) who found that at 5 years post-injury caregivers of individuals with brain injuries report significantly greater levels of stress when compared to 1 year post-injury. These authors suggest that over time family members become less tolerant of the limitations of the individual with the brain injury. They also suggest that caregivers may become exhausted by the demands imposed on them. The true meaning of this relationship in this study is difficult to understand as the nature of treatment received by the individual with the brain injury has changed dramatically over time.

It is important to note that when asked about the effects of brain injuries, many women describe positive changes in terms of themselves (personality qualities and attributes) and in terms of relationships within the family. These women describe a variety of changes including feeling stronger, more competent, more caring, more assertive, and more independent in relation to confronting the challenges of the effects of their husbands' brain injuries. It may be that although there is trauma associated with the effects of brain injuries, the positive effects tend to moderate the negative effects of the experience.

Resources

It was predicted that those women who reported a higher level of "resources" would report higher levels of "adaptation". The findings of the present study indicate a significant relationship between the first "resource", dyadic adjustment, and the measure of "adaptation", the womens' levels of well-being. This relationship between dyadic adjustment and well-being is similar to that found by Vargo (1983). In her study of women whose husbands have spinal cord injuries Vargo (1983) found that one of the six factors important to a satisfactory outcome is commitment to the marital relationship.

As indicated by the DAS, the study sample of women married to men with brain injuries report a lesser degree of dyadic adjustment than the married normative group and a greater degree of adjustment than the divorced normative group. Generally, this finding suggests that although these women experience some level of dissatisfaction with their marriages, they are not at the point at which they would divorce their husbands. It is important to note, however, that the women studied are those who have chosen to remain married, as the researcher did not investigate women who are separated or divorced from their husbands.

Another finding in relation to dyadic adjustment is that as length of time post-injury increases marital adjustment decreases. This finding is consistent with the findings of two researchers who report discouraging long-term outcomes for the marriages of individuals affected by traumatic brain injuries (Panting & Merry, 1972; Thomsen, 1989).

In terms of the qualitative analyses one theme is "changes in the marital relationship". The women describe numerous negative effects of their husbands' brain injuries on their marital relationships. These results support various researchers who describe the negative effects of brain injuries on marital relationships (Rosenbaum & Najenson, 1976; Jacobs, 1989a; Eames & Wood, 1989).

The women describe particular distress in relation to the personality changes in their husbands and the role changes that occur for themselves and the impact of both of these types of changes on their marital relationships. Many women express frustration in terms of their husbands' inability to function adequately as equal partners following their brain injuries. These findings support those of Willer et al. (1989) and Lezak (1988) who found that changes in the personalities of the husbands and changes in the degree of companionship and emotional support previously offered by husbands are particularly distressing for these women. This finding is also consistent with that of Eames and Wood (1989) who found that sudden role changes following a brain injury are a major source of stress in the marriage.

The study found a significant correlation between dyadic adjustment and coping. As marital adjustment increases there is an increase in the level of coping. There is also a significant correlation between dyadic adjustment and financial strain. As financial strain increases, dyadic adjustment decreases. This finding is consistent with Peters et al. (1990) who found that dyadic adjustment is greater when wives report a lower level of financial strain.

As a moderating influence on the "negative" effects of brain injuries on marital relationships, some women report that they are grateful that their husbands did not die as a result of his injuries. The experience seems to make them more appreciative of their husbands. It is possible that this experience, for some women, serves to increase marital adjustment and strengthen their commitment to the marital relationship.

No significant relationship was found between the second "resource", social support, and the womens' levels of well-being. As the importance of social support in mediating the effects of stress is generally well established in the literature, this finding was unexpected. This finding could be attributed to several factors. First, this result underscores the fact that for assessment purposes, the variables measured are conceptualized in very simplistic terms when, in reality, they are very complex. Each variable is multifaceted and, therefore, measuring it is imprecise. Beyond the problem of the accuracy of measuring these variables is the problem of the complex interplay of other related variables. Those women who experience decreased well-being may utilize fewer social supports due to decreased self-esteem or other factors.

Contrary to the results of the quantitative analyses, in the qualitative analyses one of the major themes to emerge is "support". Women describe receiving both emotional support and practical assistance (with house and yard work) from family and friends. Some women did, however, report a lack of support from extended family members, professionals, social services, and the government. In relation to extended family members, these women indicate that due to the "hidden" nature of brain injuries, many family members are not aware of and cannot comprehend the difficulties these women experience on a daily basis (in relation to the effects of brain injuries on their husbands' functioning). In relation to social services and the government, these women describe a lack of recognition by the government of their need for respite care and financial support.

As measured by the SSI the women in this study report a moderate level of social support. The women report that the highest source of support is their children. In addition, the statements the women made in response to the open-ended question on how they dealt with the effects of the brain injury, further emphasize the importance of children as a source of support. This finding is consistent with that of Vargo (1983) who, in a study of the adaptation to disability by the wives of men with spinal cord injuries, found that one important factor to a satisfactory outcome is children. The second highest source of support reported by the women is their husbands. This finding is surprising in view of the stress engendered by the changes in their husbands. This finding is also contrary to that of Lezak (1988) who suggests that following their husbands' brain injuries, wives lose the emotional support that they previously received from their husbands. It is possible, however, that given the relatively good level of psychosocial functioning of these men, some are aware of their difficulties, and attempt to ameliorate the stress they create by being supportive and perhaps helping with household management.

The low levels of support the women report from professionals, community groups, and special groups (designed to help with specific difficulties or responsibilities) are not surprising given the lack of such resources typically available to these women. This finding is consistent with Jacobs (1987) who suggests that there is a lack of support from long-term rehabilitation support services. This finding is also consistent with that of Unger and Powell (1980) who suggest that when families are in need of help they do not seek initial aid from formal organizations, even if the organization is designed to serve the individual's presenting problem.

The women perceive their highest level of kinds of support in terms of "altruistic" support, "which is information received in the form of goodwill from others for having given something of oneself" (McCubbin & McCubbin, 1991, p. 19). This finding suggests that in providing care to their injured spouses these women receive some form of "goodwill" in return, possibly directly from their husbands, or from other family members, extended family, friends, or community members.

The present study found a significant correlation between social support and coping. This is not surprising as the utilization of social support is a form of coping and is described as such by the women in this study.

The present study also found a significant correlation between the womens' levels of social support and the husbands' levels of education and occupational status. As the husbands' levels of education and occupational status increase the womens' levels of social support increase. This result suggests that women married to men who have more education and a higher occupational status report higher levels of social support.

Coping

It was predicted that those women who reported the greatest use of coping strategies would have the highest levels of well-being. The findings of the present study indicate a significant relationship between coping strategies and well-being. This finding supports the generally well established body of literature that indicates the importance of coping strategies in mediating the effects of stress.

As indicated by the F-COPES the overall level of coping strategies of the women married to men with brain injuries does not differ markedly from that of the normative sample. This finding suggests that women married to men with brain injuries utilize coping strategies to a similar degree as the normative sample.

The "themes" to emerge in relation to the ways in which the women dealt with their husbands' brain injuries include (a) activities; (b) support; (c) behaviors, thoughts, attitudes, and outlooks; and (d) faith. These findings are consistent with those of Karpman et al. (1985) and Willer et al. (1991) who describe similar strategies used by women to cope with the effects of their husbands' brain injuries.

The women in the study differ significantly from the normative sample on two of the five F-COPES subscales. The women in the study report less use of Seeking Spiritual Support and more use of Passive Appraisal than the normative group. In terms of Seeking Spiritual Support it is possible that the study sample which is from Alberta, Canada is less religiously oriented than the normative sample of members of the Lutheran church from Minnesota, U.S.A. and this may influence their reliance on faith or religion as a coping strategy. It is not clear why the women in the study use more Passive Appraisal as a coping strategy than women in the normative sample.

In relation to demographic variables one interesting finding is the significant correlation between coping and the age of the husband. This result suggests that women whose husbands are younger utilize more coping strategies. This may also relate to the fact that the traumatic brain injuries group are younger than the "other types" of brain injuries group. It may be that the effects of a traumatic brain injury require more coping strategies by the spouse than that of "other types" of brain injuries such as strokes. This finding may also relate to the finding of greater changes in temperament and emotionality of the men with traumatic brain injuries.

<u>Adaptation</u>

The women in this study experience a moderate level of well-being overall. Somewhat surprising is the finding that the women in this study have a higher level of well-being than the normative group, which consists of wives of men employed by the United States Army. It is possible that the time spent apart by couples in the army may have a more negative impact on the well-being of the army wives than the effects of brain injuries on the women in this study. It is also possible that the positive effects of husbands' brain injuries including, in particular, significant positive changes in the ways in which the wives behaved and viewed themselves, result in an increase in well-being not experienced by women whose husbands are in the army.

The demographic variables that are significantly correlated with well-being include the employment of the husbands and the levels of financial strain experienced by the women. As the husbands' employment status increases and as the levels of financial strain as perceived by the women decrease, there is an increase in the womens' levels of well-being (a decrease in the FWBI score). These findings suggest that women whose husbands are employed have higher levels of well-being than those women whose husbands are unemployed and that those women who experience a lower level of financial strain experience higher levels of well-being than those women who experience a higher level of financial strain.

There were two observations made by the researcher in relation to her interaction with the women who participated in this study. The first is that these women were very cooperative with the researcher and, during the telephone interview, many of them seemed to have a need to talk to someone about their experiences. The second and related observation is that some women reported a lack of resources available to them, especially those women who did not live in cities.

CHAPTER 6 - SUMMARY

Introduction

In this chapter a brief summary of the research is presented. In addition, the limitations of the study are described, implications for practice are discussed, and some directions for future research are outlined.

Summary of Results

The occurrence of a brain injury can bring about considerable change not only for the injured individual but also for their spouse and family. In recent years the family has become the focal point in the rehabilitation process for individuals with brain injuries. It is the spouse who typically carries the greatest burden of caregiving in the aftermath of a brain injury.

Sixty-two women participated in this research. The women were, on average, middle-aged and had been married for twenty years. The women generally had only one child still living at home. Most of the women had at least a high school education and just over half of the women were employed outside of the home. The husbands' brain injuries had occurred on average, 5 years prior to this investigation.

The women were interviewed briefly by telephone and were asked two open-ended questions and then completed a package of self-report measures sent by mail. The variables investigated included the levels of psychosocial functioning of the husbands, and the womens' levels of subjective burden, dyadic adjustment, social support, coping, and well-being. These variables were selected for two reasons (a) from a theoretical perspective, the choice of variables was grounded in McCubbin and McCubbin's (1991) Resiliency Model of Family Stress, Adjustment, and Adaptation and (b) from a practical point of view the resource and coping variables provide areas which might be taught, changed, or more fully developed through individual, marital, and group counselling.

Women respond to the effects of their husbands' brain injuries differently. People obviously differ in the "resources" available to them in terms of dyadic adjustment, social support, and coping. A number of conclusions can be made, however, based on the findings of the present study:

1. In response to an open-ended question regarding the effects of their husbands' brain injuries on the women, five themes emerge including changes in their husbands, changes within and for the women, changes in relationships, changes in lifestyle, and changes in support.

2. In response to an open-ended question on how the women dealt with the effects of their husbands' brain injuries four themes emerge including activities; support; behaviors, thoughts, attitudes, and outlook; and faith.

3. The husbands' levels of psychosocial functioning (as perceived by their wives) and the wives' levels of subjective burden, both measures of stress, were correlated with the wives' levels of well-being.

4. The women in the study experience moderate to high levels of subjective burden and these results are comparable to the results of previous studies reporting on the levels of burden of relatives of men with brain injuries.

5. The women report that their husbands experience mild difficulties in terms of psychosocial functioning.

6. The levels of subjective burden of the women are correlated with the levels of psychosocial functioning of their husbands.

7. In terms of the "resource" variables, dyadic adjustment is correlated with well-being whereas social support is not correlated with well-being.

8. Based on normative data, the women in this study experience levels of dyadic adjustment which are higher than the divorced normative group and lower than the married normative group.

9. The women married to men with brain injuries report that they receive the highest level of social support from their children.

10. The coping strategies of the women in this study are correlated with their levels of well-being. In addition, the women in this study use a similar level of coping strategies to that of the normative group.

11. The study group of women married to men with brain injuries experience higher levels of well-being than the normative group of women married to men in the U.S. Army.

Limitations

Limitations inherent in the present study stem primarily from the inability to sample more than a finite number of variables. It is likely that the variables under investigation in this study are not the only ones of concern to the spouses of men with brain injuries. As noted earlier, the experiences of spouses have not been adequately investigated and only extensive sampling of variables will clarify the complicated interactions between stressors, resources, coping, and adaptation.

The operational definition of the selected variables was set to a certain extent by the chosen self-report measures. It might be argued that the Social Support Inventory, in particular, does not completely measure the complex nature of social support.

Another bias is in the selection of subjects. A random sample would have included women whose husbands were not involved with either the Northern Alberta Brain Injury Society, the Glenrose Rehabilitation Hospital, or the Workers' Compensation Board.

The question of directionality must be addressed. Hypotheses for the present study were based on the literature and on McCubbin and McCubbin's (1991) Resiliency Model. The Resiliency Model is a positive coping model and it was assumed that relationships would exist between the chosen variables of stress, resources, coping, and adaptation. It is possible that a reciprocal relationship exists. Women with limited adaptation may experience more stress and be less able to access potential resources. They may perceive their husbands in a more negative light. Women with poor adaptation may also be less able to maintain a well-adjusted relationship with their husband. Women with poor adaptation may also experience lower self-esteem and, therefore, perceive less support from their social network. And finally, women with lower levels of adaptation may also be less able to access and utilize coping strategies.

The present study was an initial attempt to empirically evaluate variables related to the adaptation of women following their husbands' brain injuries. Variables were chosen because of their potential for intervention. Although the scales used to measure these variables are somewhat specific and detailed a more phenomenological approach would perhaps provide a better understanding of the complexity of the variables involved in adapting to the effects of brain injuries.

Implications for Future Practice

The critical role of the spouse in terms of rehabilitation of the individual with a brain injury points to the need to minimize the disruptive effects of the brain injury on the spouse. Attention to the needs of the spouse is essential if long-term outcomes are to be maximized.

The results of the present study indicate a relationship between stress factors inherent in dealing with the effects of brain injuries and the adaptation of wives. The psychosocial impact of the long-term effects of a brain injury on the spouse must be recognized by health care and social service agencies and policy makers. Individual and group programs specifically geared to provide information about brain injuries to spouses and other family members must be made available on a long-term basis. Several researchers in the area of rehabilitation from brain injuries have stressed the importance of the provision of information to spouses and families (Campbell, 1988; Lezak, 1986; Mauss-Clum & Ryan, 1981; Oddy, Humphrey, & Uttley, 1978; Rogers & Kreutzer, 1984). Jacobs (1989b) suggests that families become more effective case managers when they are provided with information and training regarding the long-term effects of brain injuries, problem indentification, problem solving, and resource utilization. He suggests that although families cannot be expected to meet all of the needs of the injured individuals, with support and education they can more effectively utilize other available services. Sanguinetti and Catanzaro (1987) found that caregivers who received instructions on how to deal with cognitive dysfunctions were more informed about brain injury induced behaviors and better prepared to help the injured individuals compensate for cognitive dysfunctions. Karuza, Joss, Brice, and Nowak (1983) found that the benefits of an education program for families caring for elderly relatives include increased confidence and comfort in caregiving, decreased caregiver stress, increased tolerance of elderly care recipients, improved family relations, and more effective caregiver interactions with health care professionals.

The results of the present study indicate a relationship between both measures of stress, the husbands' psychosocial functioning and the wives' subjective burden and dyadic adjustment and between dyadic adjustment and well-being. Interventions may profitably examine how to improve dyadic adjustment. Specifically, educational and other intervention programs could be designed to help couples develop effective problem solving strategies and redefine difficult situations. Effective problem solving and reframing of problems requires practice and experience and rehabilitation services should provide opportunities for couples to gain this experience.

As many women describe the importance of family support, group programs should encourage caregivers to marshall support and provide them with the skills for effectively utilizing family support. Springer and Brubaker (1984) maintain that caregivers experience difficulties in thinking about what they may need from others. They suggest several ways in which families and friends can give assistance. They present several valuable individual and group exercises for identifying support networks and describe an action plan to help caregivers assess their needs for support and their social network resources. To increase social networks for spouses, programs should go beyond the immediate family to reach extended family members and even friends, and educate them about the needs of both the spouse and the individual with the brain injury. Instead of working individually with the spouse in counselling, health care professionals could involve other family members and friends to help support the spouse. Rogers and Kreutzer (1984) describe a network intervention strategy to systematically organize and strengthen a family's support system.

Given the description of coping strategies utilized by the women, the use of these must be more clearly investigated. Perhaps "passivity" (a coping strategy that was higher in the study group than in the normative group) could be reduced if these women had more effective strategies for dealing with the stresses they experience. Also, as spiritual support was helpful for several spouses, perhaps educating the religious community as to the effects of brain injuries may be an important way to help build support for some spouses.

Some women describe support groups as a valuable resource for information and social support. Similarly, some women describe the use of community services as an important resource. Several researchers have described the importance of support groups or community services for spouses and families (Brown & McCormick, 1988; Campbell, 1988; Zeigler, 1989). Support groups and community resources can provide information and emotional support which may increase spouses' ability to deal with their circumstances.

In conclusion, this study suggests that the wives of men with brain injuries experience difficulties in adapting to the changes in their lives as a result of their husbands' injuries. Inability to cope with the stresses inherent in this situation may lead to poor rehabilitation outcomes for the injured males, marital breakdown, and/or significant personal distress. In view of this, some women adapt remarkably well. For others, however, it is essential that, early in the rehabilitation process, they be provided with information and support to assist them to better adapt to their circumstances and that this support is made available over the long-term. It is essential, therefore, that health care professionals develop a better understanding of all of the factors which might enhance the lives of these women, their husbands, and their families. In doing so, their interventions may alleviate some of the burden experienced by these women and their families.

Suggested Research

The limitations inherent within this research suggest several avenues for further research.

1. The qualitative data, obtained from the two open-ended questions asked during the telephone inteviews, are extensive and warrant further attention. It is the intention of this researcher to further analyze this data and present it in a future publication.

2. This research is an initial attempt to identify the relationships among six variables related to the adaptation process of women married to men with brain injuries. The choice of variables

was loosely based on McCubbin and McCubbin's (1991) Resiliency Model of Family Stress, Adjustment, and Adaptation. A test of this model, in its' entirety, may be useful to clarify the relationships among the many variables in the complex process of adaptation.

3. Although this research has made some progress toward identifying the variables involved in the process of adaptation of the wives of men with brain injuries, it does not address the question of how health care professionals can best intervene in order to facilitate adaptation. A logical next step of this research would be the development of treatment programs, which would provide specific strategies to enhance adaptation. For example, for each of the variables utilized and themes revealed, a series of information sessions, which would include discussions of strategies to ameliorate difficulties, could be developed.

4. In that this research focuses on women who are living with their husbands, no information is available on women who are separated or divorced from their husbands. Research involving these women would provide a very useful group for comparison. What is it that is different about the couples who separate or divorce as opposed to those who stay together?

5. In that this research focuses on the adaptation of wives of men with brain injuries, no information is available on the adaptation of husbands of women with brain injuries. Research on the husbands of women with brain injuries would also provide useful comparative information.

6. There is clear indication that children provide strong support to women adapting to the effects of their husbands' brain injuries. There is also clear indication of concerns regarding the effects on children of having fathers with brain injuries. Research on children in families in which a parent has sustained a brain injury would help clarify the effects on the children and their supportive role(s).

7. There is some indication of differences between the group of individuals with traumatic brain injuries and the group with "other types" of brain injuries. Research involving a comparison between these two groups would help illuminate the similarities and differences between them in terms of the process of adaptation of their spouses and families.

8. Further research using the modified version of the Portland Adaptability Inventory would be useful in order to test its' utility as a quick and easily administered measure of psychosocial functioning in individuals with brain injuries.

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Appendix A

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Telephone Interview

Part I

Date of Birth: Self: ____________ Husband/partner: ____________

Date of marriage (cohabition) to present husband/partner: ________________

Number of children living at home: _____ Ages of children: ____________

Number of years of education: Self: _____ Husband/partner: _____

1. 0 - 6
2. 7 - 11
3. High school
4. Some college/university
5. Completed college/university

Employment: Self: ______ Husband/partner: ______

1. Working fulltime
2. Working parttime
3. Homemaker
4. Volunteer work
5. Student fulltime
6. Student parttime
7. Retired
8. Unemployed (If so, ask about former employment)

Occupation: Self: ______ Husband/partner: _______

1. Homemaker
2. Blue collar worker
3. Skilled worker
4. Professional

Since my husband/partner's injury our family income has (check one):

1. increased_____ 2. decreased_____ 3. stayed the same_____

Please circle one of the responses to the right for each of the following statements:

1 = Strongly disagree
2 = Moderately disagree
3 = Neutral
4 = Moderately agree
5 = Strongly agree

We are experiencing financial strain.	1	2	3	4	5
There has been a change in my role(s) in the family following my husband/partner's brain injury.	1	2	3	4	5

Part 2

Date of injury: ________________

Cause of injury ____

____

Duration of coma: ________________ Estimate number of minutes, hours, days, or weeks. (No eye opening, no following commands, no words).

Duration of post traumatic amnesia: ____________________ Estimate number of minutes, hours, days, or weeks. (Confused period during which ongoing events were not regularly registered and remembered)

Skull fracture: __ yes __ no ___dk

Brain surgery: __ yes __ no ___dk Purpose if known:____________________________

____

____

Part 3

1. Please list the ways (positive or negative) in which your husband/partner's brain injury has affected you.

2. Please list the ways in which you have dealt with your husband/partner's brain injury.

Part 4

Please rate your present level of strain or distress as a result of the changes in your husband/partner using the 7-point scale below:

1	2	3	4	5	6	7
I feel no strain or distress as a result of the changes in my husband/partner					I feel severe strain or distress as a result of the changes in my husband/partner	

Part 5

For each of the indicators circle the most appropriate response regarding husband/partner's present functioning:

Irritability/aggression	0 Socially appropriate/within normal limits.
	1 Mild irritability/verbal aggression.
	2 Moderate irritability/verbal aggression.
	3 Physical aggression or severe verbal aggression.

Anxiety/agitation	0 Socially appropriate/within normal limits.
	1 Mild anxiety/agitation.
	2 Moderate anxiety/agitation.
	3 Severe anxiety/agitation.
Indifference	0 Socially appropriate/within normal limits.
	1 Mild indifference to problems.
	2 Moderate indifference - denies seriousness of problems.
	3 Severe indifference - denies existence of problems.
Depression	0 None.
	1 Mild.
	2 Moderate.
	3 Severe - disruptive for practical purposes.
Delusions/hallucinations	0 None.
	1 Mild.
	2 Moderate.
	3 Severe - disruptive for practical purposes.
Paranoia	0 None.
	1 Mild.
	2 Moderate.
	3 Severe - disruptive for practical purposes.
Initiative	0 Socially appropriate/within normal limits.
	1 Slow to get started; initiates less conversation/activity than before the injury but sufficient for practical purposes.
	2 Initiates some conversation/activity but insufficient for many practical purposes.
	3 Initiates no conversation or planned activity.
Significant relationships	0 Unchanged.
	1 Mildly disturbed.
	2 Moderately disturbed.
	3 No significant relationships.
Residence	0 Single or family residence (no support).
	1 Single or family residence (support).
	2 Structured living in community.
	3 Institution.

Social contact	0 No decrease.
	1 Mild decrease.
	2 Moderate decrease.
	3 Total isolation.
Self-care	0 Full self-care.
	1 Partial self-care - mild difficulties.
	2 Partial self-care - moderate difficulties.
	3 Needs full care.
Work	0 Same work, different work-same level, different or same work-higher level.
	1 Lower level but same general work classification.
	2 Much lower level but same general work classification or sheltered workshop or assumes and maintains regular chore schedule at home.
	3 Does not work.
Leisure activities	0 No loss of self initiated activities.
	1 Mild loss of self initiated activities.
	2 Severe loss of self initiated activities, mostly passive pursuits (watch T.V., drink coffee).
	3 No self-initiated activity ("sits and stares," "sleeps a lot").
Driving	0 No change.
	1 Increase in driving infractions and/or minor accidents.
	2 Suspended automobile license but continues to drive and/or accidents involving damage or injury.
	3 Incapable of driving.
Law violations	0 None.
	1 Minor conviction- no time served and no probation.
	2 Summary conviction or indictable offence - with probation.
	3 Summary conviction or indictable offence - with time served.
Alcohol use	0 None.
	1 Mild use (social).
	2 Moderate use.
	3 Problem drinking.

Drug use	0 None.
	1 Mild use
	2 Moderate use.
	3 Problem drug use.
Social interaction	0 Socially appropriate/within normal limits.
	1 Occasional inappropriate behavior.
	2 Frequent inappropriate behavior(childish, silly, out-of-place).
	3 Practically complete lack of appropriate behavior.
Walking	0 No detectable impairment or no increase in preinjur impairment.
	1 Walks unaided but with a limp.
	2 Walks with cane, crutches, or walker.
	3 Cannot walk even with aids.
Use of hands	0 Neither hand impaired or no increase in preinjury impairment.
	1 Only nonpreferred hand impaired.
	2 Only preferred hand impaired.
	3 Impairment of both hands.
Hearing	0 No impairment or no increase in preinjury impairment.
	1 Slight impairment relative to preinjury impairment but within socially useful range.
	2 Lacks reliable or useful social hearing.
	3 Practically deaf.
Vision	0 No impairment or no increase in preinjury impairment.
	1 Slight impairment relative to preinjury impairment.
	2 Impairment sufficient to require glasses or change in preinjury prescription or to interfere with ordinary activities.
	3 Practically blind.
Speech	0 No impairment or no increase in preinjury impairment.
	1 Mild - easy to understand.
	2 Moderate - difficult for strangers to understand.

	3 Severe - incomprehensible or no speech.
Language	0 No impairment or no increase in preinjury impairment.
	1 Mild-has adequate communication skills for most conversation and practical purposes.
	2 Moderate-some communication ability insufficient for many practical purposes.
	3 Severe-insufficient for practical purposes or absent.

Appendix B

Cover Letter

Dear ____________________,

Thank you for agreeing to participate in this research study which deals with various factors related to your experience as the spouse/partner of an individual with a brain injury. This study involves you completing five self-report measures about your level of burden, marital adjustment, social support, coping, and well-being.

Participation in this study is strictly voluntary. I would appreciate your cooperation in completing the enclosed self-report measures and consent form. The self-report measures should take you approximately 45 minutes to complete. Once you have finished, simply put the measures and consent form in the accompanying envelope and drop it in the mail. All postage is prepaid. Please return the self-report measures and consent form **as soon as possible**.

This is a survey of your experiences and there are no right or wrong answers. There is no need to put your name anywhere on the self-report measures and all responses will be kept confidential. The data from the study will be used to help determine what support would be most helpful for the spouses/partners of men who have sustained brain injuries and will form the basis of the dissertation for my Ph.D. degree.

The questions asked in the self-report measures should not create emotional distress for you. However, if you feel that you need help in dealing with your level of stress, or if you have questions concerning the study or the measures used, please feel free to contact me at 471-2262 ext. 2677 (work) Thursdays and Fridays during the daytime or at 433-1897 (home) at any other time. If you are calling long distance please call me collect, person to person, at home. You may also request a copy of the final results of the study by calling either of those numbers. I greatly appreciate your participation in this study and thank you for your assistance.

Sincerely,

Penny Ford

Appendix C

Consent Form

PROJECT TITLE:	Wives' adaptation to husbands with brain injuries.
INVESTIGATOR:	Penny Ford, M.Ed., C. Psyc. (Alberta) Glenrose Rehabilitation Hospital
PURPOSE OF STUDY:	To investigate six variables related to the adaptation of the wives/partners of individuals who have sustained brain injuries. These variables include your levels of subjective burden, marital adjustment, social support, coping, and well-being, and your husband/partner's level of psychosocial adjustment.

I agree to complete this consent form and four brief self-report measures which will take about 45 minutes.

The investigation carries no apparent risks to me. All information will be coded so that it cannot be identified with me or my spouse/partner and no names will appear in any documents or reports.

I may not benefit directly from this investigation, however, it is hoped that this investigation will provide further information and support for the development of programs for the spouses/partners and families of individuals with brain injuries.

I UNDERSTAND THAT I can refuse to answer any questions on the self-report measures that I prefer not to answer.

I FURTHER UNDERSTAND that I am free to withdraw my consent and terminate my participation at any time, without prejudicing present or future rehabilitation services to my spouse/partner or myself.

I HAVE BEEN GIVEN THE OPPORTUNITY TO ASK WHATEVER QUESTIONS I DESIRE AND ALL SUCH QUESTIONS HAVE BEEN ANSWERED TO MY SATISFACTION.

I UNDERSTAND that my signature means that I have read this form, understand my involvement in the study, and that I **voluntarily** agree to participate.

I UNDERSTAND that the information collected for this particular study may also be re-analyzed in the future in the investigation of other research questions.

Any inquiries concerning the study can be obtained by contacting Penny Ford at 471-2262 ext. 2677 (work) during the daytime on Thursdays or Fridays or at 433-1897 (home) at any other time. If you are calling long distance please call collect, person to person, at the home number.

______________________________	______________________________
Signature of Participant	Date
______________________________	______________________________
Signature of Investigator	Date

APPENDIX D

Statements Generated by the Two Open-Ended Questions

Question 1. Please list the ways (positive or negative) in which your husband's brain injury has affected you.

Positive

01 Husband is at home more and I enjoy his company.
01 Better - changed life.
02 I'm no longer shy and withdrawn. It brought me out of my shell.
02 My family depend on me.
04 Pride in knowing you did your very best for someone you love.
05 I became more assertive.
05 I became a survivor.
05 I developed the patience of Job - although I think I've lost some of it the past couple of years.
05 We're closer because we're so open about it.
06 Brought family even closer together.
07 I became very protective of him, watchful.
08 Life is more precious.
08 We are closer as a family.
08 I care about him more than before.
12 I had to be stronger.
13 I had to re-examine the whole relationship and decide which things were important to me. I've gained a better understanding of what's important to me.
14 Made me more independent.
14 You have to cope with things, you stick by.
14 It toughened me up.
15 At first it was definitely negative, now I'm looking at it as positive, we've still got him.
15 I found strength after this, I had it all along but never used it.
26 It's made me a lot stronger.
26 It's made us closer.
26 It's made us more patient.
26 It's made us more aware of a lot of things - what's important.
26 What kept us going is knowing how lucky we are that he turned out so well.
27 Family and friends rallied to support us, people were kind to us.
28 It changed my attitude toward people with injuries.
29 A plus was that it made me go back to school.
29 Out of it all I became a very much stronger person - but I think there are easier ways to grow!
29 I've become very compassionate to others i.e., any survivors.
30 Before the accident he was head of the household and I was a shy person with a poor self image and lots of fears. I underfunctioned in the relationship and he overfunctioned.
30 While he was in hospital I had to stand on my own feet and the surprise was that I could do it.
30 I have become much stronger.
31 Emotionally it has made me stronger.
31 It has given me more confidence in myself.
31 I had to handle everything myself and I was successful.
31 It has made me mature.
31 It's made me appreciate him and our family more.
31 It's helped me to appreciate my small town because we've lived here a long time and people stood behind us - there was strong support.
31 All the churches prayed for us.
34 I'm grateful he's here.
52 In some ways it's made me a more independent and stronger person.
55 For the first little while it made me grow up more.
64 It's made me a lot stronger.

64 It's made me more aware of life itself.
64 It's made me more appreciative.
64 It's made me a better person.
68 I've come to know the Lord in this time.
68 I have more compassion for others.
68 I became a more caring person.
68 It made me realize how much I do care for him.
68 I don't take him for granted anymore.
70 It has made us much closer as a family.
70 I have more compassion for people, especially regarding people involved with impaired drivers.
77 I grew, I do things I didn't think I could do.
77 Now I know what I'm capable of.
78 I'm more tolerant/understanding of people with disabilities in general.

Negative

01 Whole new ballgame - life is very stressful.
01 Lost social contact.
02 It's been hard on the children - especially our oldest daughter - especially when she can outsmart her father.
02 He will side with the children rather than discipline them.
02 There has been trauma this past week as my husband has talked about wanting out of the marriage.
03 Mental abuse (not physical).
03 Stress of having to take over the whole family.
03 Lack of support medically and from social services.
03 Disrupted whole life.
04 Children lost their teen years and had to grow up too fast.
04 He was very abusive both verbally and physically.
05 He became more aggressive.
05 I need coping skills that I don't have.
06 Totally responsible for his care.
06 He was unable to assume his role as a father.
06 He was unable to assume his role as a spouse.
06 Too many demands on my time.
06 Lots of stress.
06 Lots of guilt especially regarding looking for fulltime placement for him now.
06 Guilt for not being as good as one could.
07 I had to take over all decisions
07 I had to take over all responsibilities.
07 It is like having two teens in the house.
07 He's had growing pains.
07 He's had mood swings.
07 He's demanded a lot of my attention.
07 I've been torn between attending to him or to the children.
08 A lot of patience is required. I have to find patience many times.
08 Mentally/emotionally drained many times because of his frustration (not able to move around, attend choir).
08 As a result of the injury there are so many more responsibilities - I get drained.
09 More decision making.
09 He really relies on me now, he likes me to be there at all times.
10 Changed our lifestyle.
10 I have to make most of the decisions.
10 I have to do everything.
10 I have all of the responsibility.
10 I have to have more patience.
10 We just can't get up and go and do things.
10 It's changed our way of life.

11 He leaves things sit for months.
11 He's too secretive with me - he does things behind my back.
11 He wants everyone to sympathize with him.
12 Had to take control of everything.
12 Had to be stronger.
12 I have to do everything - pay bills, etc.
12 Lots more responsibility.
13 I had to make a lot of decisions and organize him - I did this longer than necessary.
13 I had to stop mothering him.
14 Take on all the decision making.
14 No one to discuss decisions with.
14 More stress.
14 A lot more concern because I worry.
15 It's just my duty to take over responsibilities.
16 Loss of husband.
16 Loss of father.
16 Loss of income.
17 The last year has been really rough.
17 He has not been working and his being home all the time is difficult.
17 There are fights between the kids and him.
17 I haven't recovered yet.
17Not being able to have sex, no sex for a while, we're just not getting along.
17 We don't see eye to eye.
17 I have be the referee between him and the kids.
18 It is very hard to get along with him.
18 Being at home can be very tense rather than relaxing.
18 It's put a lot of pressure on me.
18 He gets mad or loses his temper with our 3-year-old son but at this point there does not seem to be much effect on our son.
19 I don't have an equal partner because he can't make decisions or be supportive.
19 His functioning is quite variable.
19 There are a lot of things he can't do physically.
19 I take care of the kids and until last year I couldn't leave them alone with him.
19 He can't help me plan for the future.
19 He is self centered.
19 All the heavy work is mine now
19 All the worries about the future are mine now.
19 I can understand how men feel frustrated being the head of the household.
21 It's a real strain because he gets mad easy over anything - any little thing.
21 He's so totally out of character.
21 I have to do more things and take over business responsibilities.
21 Everything has to be <u>his</u> way.
21 He complains that nobody talks to him or listens to him - his conversation is monotonous and perseverative.
22 Significant financial pressure.
22 His emotions are at the surface, therefore, we have to deal with him - tippie toe.
22He has no short term memory, therefore, things we may discuss and agree upon, he can't remember - creates a web of unhappiness.
22 He has violent outbursts.
22 He's tired, affected by the cold, and has seizures which all affect the family.
22 My relationship has become maternal - I have 3 sons instead of 2.
23 Times where he just bugs me since the accident.
23 There are some changes, irritating, but I live with them.
24 Extra stress and responsibilities.
24 A lack of direction for the future because of his lack of direction.
24 Overall increase in stress level.
24 It has affected how much I can rely on him - for example to take over the running of the household and manage with the three kids as he did before.

27 It's been negative - a lot of work and strain.

27 He's dependent.

27 The marriage has died.

27 He's like another child.

27 It really negatively affected our 18-year-old son.

28 There was a change in lifestyle at first. He was in hospital for 4 months.

28 It was very difficult to take care of everything by myself.

28 There was a role reversal for about a year while he was at home all day.

28 It took a long time for his memory to return.

29 Social isolation.

29 Financially.

29 I began to live and breathe brain injury.

29 It gave me so many new roles to play.

29 I lost my identity for a while. Life revolved around the family. It was very difficult to pull myself out of all of that.

30 My newfound strength would have been welcomed before the accident but now he perceives it as negative because he sees himself as weaker.

30 He's home all the time and it's been a strain to get used to being under the same roof all the time.

30 In some ways he's different but in other ways he's the same but much more extreme - what has been heightened is frustrating for me (i.e., his worser qualities).

31 We did struggle.

31 He suffers from depression.

31 He's not able to work as he did before - he was very active in the community.

31 It hurts to see him going through this.

31 I worry about him.

31 The workload in the office was greater (owned a business)

31 I was disappointed in the little support we received for the family from the hospital.

31 It affected our young one who had a psychologist.

33 Before I worked for pleasure, now I work because I have to.

33 Before he had his driver's license I had a lot more responsibility - especially driving the kids around-this has changed now that he has his license.

33We were active in sports but now we don't play ball, ski, etc.

33 Family activities have declined and are at a minimum.

33We don't travel much anymore. Our lifestyle that was has changed. We used to travel to southern and northern Alberta and Saskatchewan to visit family.

33 Socializing has decreased.

34 Having to take control when I would rather have him do it.

34 He's not as easygoing - so it's more stressful in dealing with him.

34 I'm frustrated sexually.

34 I'm frustrated that I can't provide for the family in the same way as he did.

34 I'm frustrated with finances, not being able to pay bills and getting behind.

34 I'm frustrated with the government and their lack of financial support/assistance.

35 Taking over major decision making. He's not capable of making a decision.

35He gets aggressive very quickly - he has a very bad temper.

35 He doesn't care where he pulls a temper tantrum - which creates a lot of embarrassment.

35 Our 13-year-old won't bring friends home - it's really hard on him. They used to do so many things together.

35 I feel resentment.

35 I hate making decisions, but I have to do it.

35 I miss him (she started to cry).

35 He's very antisocial and he ignores my three children from my previous marriage.

36 It has taken a lot of understanding and patience.

36 I have spent a lot of time with him.

36 i have had a lot of sleepless nights.

36 it is very stressful. There are a lot of worries and concerns and it's hard to take.

37 I have to be more aware of financial things. He pays the bills but I have to monitor him.

37 I have to watch him regarding cooking, mowing the lawn, etc.

37 I wonder if it's going to happen again. This creates stress. I am not as relaxed about things as before.
37 I watch what I cook in order to prevent a heart attack.
37 I do all his medical forms.
40 I have to make all the decisions by myself.
40 I have to do most everything by myself. I never had to do that, he was the strong one.
40 Our social life is not anything anymore.
41 When one person in the house has a brain injury everyone has it.
41 I've had such a shock - it's thrown me.
41 I've completely changed - having had to take charge.
41 I used to be bubbly/sparkly, but something "died" in me.
41 My world is just topsy turvy.
42 I feel I have to listen and make sure he makes the right decisions.
42 We're (the family) more careful not to upset him.
42 Just the upset of it all, the trauma of it all, I was pregnant when it happened.
44 I've had to take charge of everything.
44 I've had to do all the driving.
44 I've had to really counsel myself to have patience with him.
44 He's very dependent on me.
45 It's been difficult.
45 My husband's psychological problems have increased dramatically since the accident.
45 He feels sorry for himself.
45 He's suicidal and homicidal
45 He can't do what he did before.
45 He has memory problems.
45 I've had to spend a lot of time with my husband.
45 He relies on me more than he should.
46 He depends on me more.
46 His personality isn't the same.
46 He gets frustrated easily and his temper is uncontrollable at times.
46 He's just not the same person he was before.
46 I get frustrated with him a lot - he's childish at times.
47 He's not quite himself - he has mood swings.
47 He's frustrated.
47 He wishes he could do more stuff.
47 He's always angry at the kid.
47 It's hard for me because I can't do anything to help him.
48 His temper, he's not the same - he gets emotional fast.
48 He is not the same person.
48 He doesn't take the pressure as he used to.
48 He has mood swings - which cause stress for me.
49 At the beginning I had a lot of adjusting to do.
49 His personality has changed completely.
49 He gets very angry over the least little things.
49 He doesn't sleep well.
49 He is very unhappy.
49 He can't do things like cut the lawn, clean the sidewalk, etc.
49 I had a nervous breakdown 2 years ago.
50 I have more responsibility.
50 I have to be more organized.
50 I have to have lots of patience.
50 Everything changes so much.
50 It's like dealing with a totally different person.
50It was like babysitting at first.
51 We've had to change our whole way of living - socially, mentally.
51 Everything we did before we couldn't do.
51 The kids suffered the worst.
51 I couldn't give the kids the attention they needed.

51 My husband became like a child.
51 Emotionally he can't go to social functions, so I have to go by myself to things like weddings and funerals.
51 He can't do any jobs like changing the oil.
51 I have total responsibility.
51 I have to be both mom and dad to the kids.
51 The kids missed out on their dad.
52 He had a real personality change which has indirectly affected me.
52 I've changed - I was very dependent on him before.
53 Every now and then I worry about it and how it's affecting him.
53 It's always there in the back of my mind.
53 I worry about the soft spot in his skull.
54 Sometimes he gets quick tempered and pushes or shoves me.
54 He's a bit slower at work.
55 The main thing was I had to do the driving.
55 He can't put up with noise as much as before, therefore, I had to keep the kids quiet (they were young when this first happened).
56 It's changed our lives completely.
56 There is a high stress factor.
56 Before this happened I was ready to update my education but then it happened and I couldn't.
56 I've given up a lot - I feel bitter about what I had to do - I don't like my work.
56 It's been very difficult for my daughter at home.
57 I go to work and come home and there is not much difference (I work in a hospital).
57 There has been financial stress.
57 I get tired.
57 I want to get out of it but don't know how.
57 I've given up a lot, family-wise, in the past couple of years as he has trouble accepting my family.
57 It's caused wear and tear on our relationship.
58 I can't do things the way I want because I have to stay home.
60 I can't go out to work.
60 I have to be with him constantly or else his mom and dad have to be with him.
60 It's a lot of strain with his temperament. I know when to talk and when not to talk.
60 It's been especially hard on the children, the children went through hell. I would like to see a program for the children.
60 We lost a lot of friends.
62 Finances are a problem.
62 I worry a lot because he gets blackouts, especially when he's out alone.
62 He doesn't remember where he puts things and then he blames the kids and he gets into a temper.
62 It's more stress on me, I worry a lot.
62 When he gets angry I have to keep quiet.
63 We have to keep ourselves on a budget.
63 It's like having another kid in the house.
63 His anger gets out of control.
64 It's changed my life totally.
64 I take care of everything, I do it all.
64 It was really very scary at the beginning. He was very aggressive and we were afraid that he would stay that way. He said everything and anything.
65 He seems to depend on me for everything.
65 I have to monitor his finances or he'll spend the money without paying the bills.
66 In a sense I'm living with a perpetual teenager.
66 What was affected is his reasoning ability
66 What was affected is his ability to control his emotions.
66 I lost my partner - I have more of a dependent.
66 I've become "hard" - as an insulation for myself so I don't get hurt by my husband's actions and words.
66 I'm not as carefree or easygoing.

66 I've dealt with a lot of guilt because I didn't like him anymore.
67 I used to be a lot more understanding of my husband.
67 I'm a lot more judgmental of my husband.
67 There was a time when I had no expectations of my husband, now I have a lot more.
67 I used to give my husband more credit for being his own person.
67 I worry more about our relationship.
67 I will override my husband on decisions/actions re: the kids - I'll openly contradict him.
68 I was a little afraid that he was becoming too dependent on me but that has changed since he's been out of the hospital.
68 It's been really hard watching someone I care about suffer and knowing there was nothing I could do.
69 He gets angry.
69 He gets very nervous - fast.
69 I need a lot of patience for him.
70 Doctors don't know how to help.
70 I've had to fight to get documentation regarding areas he's not functioning in.
70 It's been difficult watching someone I love struggle with self-esteem and self-concept.
70 My husband was high up professionally and he still functions extremely well but at a lower level for him and, therefore, others don't see the loss.
70 Others don't understand what he can or can't do e.g., his employers - his behavior appears inconsistent - and he finds that embarrassing and confusing and hard to explain.
70 There was incredible pressure for him to quit and stay home, therefore, he was penalized for wanting to keep going.
71 He gets deeply depressed and thinks things that aren't true.
71 It's given me some really difficult times, worries, problems.
72 I have to remind him more, he forgets easily. His memory is getting worse over time.
72 Mood changes - he gets depressed easily.
73 I had no one to talk to, his family did not support me - they went against me.
73 In the first year him not remembering was very difficult.
73 In the first year I had to be mother and father to the kids.
73 In the first year there was a lot of mental and physical strain.
73 The first year was the hardest because of the loss of security.
73 The first year was the hardest because of the unsureness of what would happen because of his temper swings.
74 I don't have time to myself anymore.
74 I don't laugh like I used to do.
74 I have a lot more responsibility.
74 I'm a lot more tense than I used to be but I haven't resorted to meds.
74 I'm alone a lot now.
74 I'm emotionally fatigued a lot.
74 I'm tired a lot.
74 We don't socialize like we used to.
74 We tend to do more socially with people he's known a long time to reduce the stress on him.
75 He's like a totally different person.
75 I feel I don't have a life.
75 It affected every way my life.
75 It affected me emotionally - there is no more affection between my husband and myself, no more love, everything is gone.
76 A lot more strain, a lot more pressure.
76 Change in lifestyle.
76 He gets language and thoughts mixed up.
76 He has trouble travelling.
76 Our lives are so different than they used to be.
76 Total change in his personality.
77 My role changed, we used to share everything (duties, work, children), now everything is my responsibility.
77 Sometimes it's just too much, sometimes I wish I could share everything with my husband.
79 He gets angry at himself because he forgets things.

79 He used to be quiet and nice, now he's angry and nobody can do anything right.
79 I have to guide him through things he used to do on his own.
79 If he would have been alright when I got hurt I would have had some support.
79 Lots of things he used to do he doesn't remember to do.
79 Mostly I've taken on most of his roles, everything was dumped on me.
79 Our sex life is down the tubes.
80 Emotionally speaking it would really upset me because he would be screaming and yelling at me and the kids, my nerves were getting wrecked.
81 Any little tasks we took for granted he can't do, for example, household and car repairs, even changing the oil, he did everything on the cars and now we have to hire someone to do these things.
81 He gets very frustrated and angry and then he gets irritated if I try to help him.
81 He has poor balance and coordination and he suffers from bad headaches.
81 I can't go away anywhere.
81 I can't leave him alone.
81 I get nervous leaving him at home. He falls and I've had to take him to emergency three times because he poked his eye.
81 I worry all the time.
81 It's a constant worry, 24 hours a day.
81 It's made me have to do everything, he doesn't drive, I'm the sole breadwinner, and he can't fix/repair things.
81 It's really changed us. We used to be very active with golf, curling, and fishing, but now he can't do anything anymore. He can only do a little gardening.
82 He doesn't handle things as well as before.
82 He's quite nervous.
82 His memory is poor.
82 We've had a lot more stress.
83 Emotionally it's really hard on the kids and it's hard for me to see this.
83 He can't be "caring" - he thinks it's enough to support the family.
83 He can't show the kids love.
83 He overreacts to little things
83 He's angry all the time, and quick to anger - sometimes I'm afraid of his anger.
83 He's mentally and verbally abusive (not physically) constantly.
83 He's tight with money.
83 He's very prejudiced - even more so than before his accident.
83 I cry a lot.
83 I feels as though I'm between the kids and him.
83 I get blamed for everything.
83 I have to push him to get things done.
83 I have to take money out of groceries to get things fixed.
83 Things have to be his way.
84 He cannot hear too well-he cannot understand me.
84 He forgets everything.
84 If he's sick it causes me a problem because I worry about what goes on in the house. I know he's not feeling good, he gets dizzy, and I'm worried he'll fall.

Question 2. Please list the ways in which you have dealt with your husband's brain injury.

01 Reading.
01 Support group was helpful but too short - people don't put time aside.
02 Contact with friends - time out with them. I have a close knit circle of friends.
02 Read.
02 I listen to a particular family program.
02 Friday nights out.
02 I <u>had</u> to manage.
02 Having three children after the injury helped me cope.
02 Moving to a smaller town was helpful.

03 Overlooked many things - not his fault.
03 Just deal with it.
03 Family support.
04 Becoming involved in volunteer work.
04 Trying to help others.
04 Hope that there would be help.
04 Live day by day - not look to the future.
04 Look for the good that happened that day.
04 Look for any little improvement.
04 Being positive.
04 Kids feel where others fail it's because they don't involve the kids - the kids appreciated being involved.
04 Kids were and are a tremendous support for me.
05 Very open about it - doesn't hide it.
05 Taken him to various doctors and professionals.
05 I'm a very logical thinker, which was positive.
05 Assertiveness.
05 Patience.
05 Sometimes escape by going to sleep.
06 Christian faith.
06 Accept they (the family) can't do everything.
06 Get the help that is helpful to my husband.
06 Initially had homecare but don't want to go back to that because it's an intrusion.
06 Had a cleaning lady for a while.
06 Got funding.
06 Learning to pace myself - key thing.
07 I send him to a psychologist.
07 I keep accepting the way his is.
07 Day to day accept things.
07 Try to understand.
07 Try not to put too much pressure on him - helped me recognize what he couldn't do.
08 Doing a lot of praying.
08 My faith keeps me going.
08 Just keep on going.
08 You have the strength when you have to do it.
09 Gone to NABIS
10 Being very positive.
10 Life has to go on.
10 We make the best of it.
12 Common sense.
13 Take charge.
13 Belonged to a womens' support group in order to work through my own feelings.
13 When my husband was in the hospital I wasn't a passive observer. I was active in his recovery. I spent hours with him.
13 I talked to people at the hospital re: what was happening - in order to feel in control.
14 When I get down I call my mother.
14 When I get down I call my best girlfriend.
14 I've talked to my doctor about it.
14 I go on a little shopping spree - it's just a little lift.
15 Talked about it.
15 Everyone around me was supportive.
15 I've learned to cope with it.
15 I've learned to live with it.
16 Keeping on working.
16 NABIS to a small degree.
16 Going to university.
17 I tried to get counselling through Family and Social Services but have been unable to due to limited resources in small community.

17 Career Connectors in our small town have given me some help.
17 I go to church on a regular basis.
18 I go to work.
18 I put up with it.
18 I don't want to put negative feelings against my husband with my family so I don't talk about it with them.
19 My general attitude is, this is the problem so let's find a solution.
19 I am not a quitter.
19 Find a solution and go ahead and do it, cope, deal with it.
19 My husband and I see a psychologist.
19 My husband goes to two anger clinics.
19 My husband goes to a relaxation clinic to learn how to deal with anxiety.
19 I find resources for the problems.
19 At the time of the accident it was hard to get information and so I had to get it myself.
21 I try to work extra hours if I can, just to get away.
21 We did see a psychologist, but it was more for my husband.
21 I just hope things will get better.
22 My husband has become a recluse so I've become more outgoing in other areas of my life to compensate.
22 I spend more time at my job.
22 I do more things that are work related e.g., conferences - which don't include him and are a form of escape.
22 I was a perfectionist and had to change because he would never meet my standards. I changed my standards.
22 People don't really understand what happened, therefore, I don't count on old friends, so I've developed another support system - one good friend.
22 I concede a lot of things because I can't follow it up - it upsets my husband too much.
22 We moved back to the city to facilitate my employment and better medical attention for my husband, and he's improved greatly since we moved.
23 Sometimes he's like a teenager and I deal with him as I would my teenage sons.
23 Sometimes I just tune him out.
24 I have taken on the required responsibilities.
24 I have adjusted time schedules, personal and family in order to accommodate the changes.
24 I have dropped activities that I may have done before - extracurricular things - clubs, community organizations, school things.
24 Counselling.
24 Retreated.
26 Need to just keep fighting and going on.
26 Accepting that it happened and accepting that the changes in him are permanent and then just going on.
26 Big change in everyone's life and just need to keep fighting and moving forward.
26 Lucky to have the kids - they helped me and came through it as well as I did.
26 Lots of support among family members.
26 The kids handled it so well - it helped me.
26I went to a NABIS meeting when I was at a low ebb and came out feeling sorry for everyone else who seemed worse off than me.
26 After a year we went back to the university (hospital) and it was then that we accepted that is how he is going to be.
27 I had the financial resources to make a go of things.
27 Our church and my faith.
27 I saw a psychologist at NABIS and had a one hour session with her which I found very helpful.
28 Initially difficult because I didn't want to ask for help.
28 His relatives did little things to help like mow the lawn.
28 I had to overcome my belief that I could "do it all".
28 A friend volunteered to look after the kids.
29 I went back to school, took upgrading, became a psychiatric nurse.
29 Began a brain injury support group for central Alberta.
29 Joined a church organization.

29 I'm in the process of developing a support system to start in the emergency room.
30 I took a caregivers class at the Glenrose.
30 I do a lot of reading. It helps keep me sane - I read especially on the topic of brain injury.
30 A psychologist friend has been a good support to me.
30 I keep a journal on the recommendation of my psychologist friend.
30 A whole lot of praying.
30 Church has been a big support. The church has also started a support group for dysfunctional families which I attend.
30 Family has been a big support.
31 I talked to our family doctor.
31 My husband did go for therapy but his psychologist couldn't give me information for me to help him.
32 I prayed.
32 I took one day at a time.
33 Church has supported us 100%, helped with the kids, helped spiritually.
33 My husband's company has been ace - drove him to and from the Glenrose and invites us to company functions.
33 I stuck it out with my friends - being able to talk to friends about it.
33 My work keeps me busy and active.
34 We've been together half my life, he's part of me, anything that happens I can accept.
34 I can love any changes in him.
34 Knowing how fast time goes by.
34 Take things a day at a time.
34 Focus positively.
34 Try not to be bitter or selfish - I put myself in his shoes and see it from his point of view.
34 A lot of times I tend to forget about it.
34 I don't dwell on it.
34 The more time goes by the more I accept how things are, things are improving.
34 I don't expect things to be the same.
34 I'm willing to accept him.
34 I'm grateful he's here.
34 I would never consider leaving him.
35 I had to learn to put my foot down, to be firm with him, sometimes I treat him like a kid, and even yell at him. (At first I had let him make financial decisions and we got further and further into debt.)
35 I have to make him do things to keep his brain active.
35 I have to keep praising him.
36 I have friends over.
36 I've had support from family.
36 I've had to accept it - that makes it easier.
40 I take one day at a time.
40 I won't give up.
40 I'm grateful for every little improvement.
41 I live one day at a time - some days are better than other days, depending on his moods.
41 I go to my job and get out of the house.
42 At first I had unrealistic expectations, but now I don't.
42 I don't get upset at his outbursts, I just accept them as part of his injury.
44 I give myself time - time to myself to get away - I go for walks.
44 I need to wean him (from me) - he's very demanding.
44 My three children were there at the time of the accident and provided support.
44 My oldest son will call and come out and see me now, especially when I sound upset.
45 I've tried to sit back and talk to him - try to help him remember things.
45 I've got more into doing crafts
46 I work.
46 I keep busy.
46 I curl.
46 I have friends I see.
46 I try to ignore a lot of things going on - put them out of my mind.

47 I try to help him out as much as I can.
47 I leave him alone - he seems to get better if no one is bothering him.
47 I try to be there when he needs me.
48 I take things day by day.
48 I don't think back on the accident.
49 My psychiatrist helped me a lot.
49 I use medications.
49 I've done a lot of talking to myself - to cope and not get annoyed with myself.
49 I accept one day at a time.
49 I have good neighbours and friends.
49 I have a lovely little granddaughter.
49 I accept what happens.
49 My husband attends counselling.
50 When he becomes frustrated I sit down and have discussions with him.
50 I have to let him try and learn or make him do it.
50 I have to insist a lot, demand, push.
50 He picked up bad habits e.g., watching T.V., and I had some problems to get him to go out and communicate with others.
50 I had to simplify a lot of things for him - to explain routines - because his logic was screwed up. He would go from a to c and miss b.
50 I had a lot of patience.
51 I just went on with life.
51 I try not to dwell on the accident and to not use it as a crutch. I think I did for a while.
51 Life goes on.
51 I do the best I can.
51 I've changed a lot of my entertainment e.g., We used to dine out and have friends over but we can't do that now. We also used to curl and golf but now I go out camping with the kids and play cards.
51 I have to live with it.
51 My son has provided tremendous support - he stays with me half time.
52 The kids have been a wonderful form of support.
52 I took RN training as a way of dealing with it. I had trouble being dependent on the government for a living. RN training was an escape route.
52 I have a really positive attitude - today may be bad but tomorrow will probably be better.
52 I keep busy and find things to do.
53 I was very supportive of him - he was worried about the hole in his head.
53 Just carried on.
53 Both sets of parents came to help originally.
54 I back down if there is an argument.
54 We moved out of the city - he feels more protected because tornados don't like trees.
54 I watch what I say.
54 I don't bug him about things.
54 I want to help him if I can rather than leave him.
54 We sought marital counselling.
55 It was just minor brain damage so I just had to keep the kids quiet - noise distracted him.
56 It required a total readjustment of my life.
56 I had to assume all responsibility.
56 I deal with it as it happens and does not happen.
56 I've learned to watch for the signals because there is that area of moods and mood swings - he's very unpredictable.
56 I've learned to adjust myself to his moods.
57 Going to work, it's my escape.
57 I get away - to visit my daughter in Calgary.
57 My time is mine.
57 I don't sacrifice myself anymore.
57 He does his thing, I do mine.
60 Take one day at a time.
60 I can calm him dow

60 We've gotten used to it.
60 I gave some land back so we could cope with it.
60 I think it helps a lot to be on an acreage.
60 It helped to have an informal support system with two other women whose husbands had had brain injuries.
60 I go skiing with my daughter.
62 I don't say anything when he gets angry.
63 Being at the Glenrose.
63 We're getting family counselling - my son was hurt as well.
64 My husband had a wonderful doctor who brought me articles in the hospital.
64 I do what I have to do.
65 I believe in God and I pray.
65 I get support from my eldest daughter and grandchildren.
65 I attend the caregivers group at the Glenrose.
66 A job - I call it my mental health job.
66 I have lots of outside interests. I do things on my own.
66 I've insulated myself against him.
67 Everyday we sit down and talk about how we're feeling.
67 He took a stress management course twice and I took the second course with him.
67 He saw a psychologist.
67 I saw a psychologist - just a couple of times.
67 Communication is the biggest thing.
67 It takes more work to work things out.
67 We go out and be a couple and have fun.
67 Sometimes we've stayed away from people in order to have time alone.
68 I found the Lord.
68 I did a lot of praying.
68 I get my strength from the Lord.
68 My sister-in-law was there for me, she was someone to talk to.
68 Being able to talk to my husband, about what was happening, helped.
68 We saw a social worker for a while and may go back again.
68 I spent a lotof time at the hospital.
69 I use patience, lots of patience.
70 As a family we're extremely open about talking and laughing about it (the brain injury).
70 I've tried to be informed about injury - which areas have been affected.
70 Teasing and joking about it works well for us as a family.
70 We're very aware of support groups but don't use them - my husband finds them too negative.
71 I just couldn't care anymore.
71 I try not to get terribly depressed and not care as much.
71 I've given up things.
72 I attend counselling - a company rep. comes out to the house and provides counselling.
72 We talk about it-we have good communication.
73 I have a good girlfriend who listened and gave advice.
73 I kept in touch with the neuropsychologist.
73 I took it upon myself to go to the library and get information on brain injury.
73 We have a good family doctor who listened and gave advice.
74 I just really tried to stand by him.
74 I try not to make him dependent.
74 I try to keep problems to myself.
74 I try to once in a while get out with my own friends.
74 I try to reduce the stress on him.
74 We try to do things socially together-like movies.
75 Children provided support that I didn't get anywhere else.
75 I buried myself into my work.
75 I cried a lot.
75 I had counselling help.
75 If I didn't have the children I don't think I would have survived.
76 Trying not to get frustrated - step back from the situation when things occur.

76 We see a counsellor.
77 I talked to a counsellor at a rehab centre.
77 I talked to a doctor.
77 I tried to keep my spirits up.
77 In many ways I was too busy to help myself - I concentrated on my daughter and husband.
77 It helped to have little time to think and dwell on it.
77 It was important to stay together as a family.
77 Learning about it and having directions of what to do (from professionals) was helpful.
77 We tried to keep as normal a life as possible.
77 We were able to give up things to cut back on finances.
79 I love my husband and don't want our marriage to end - the fact that we care about each other keeps us together.
79 I'm getting counselling.
79 I'm in a support group for people who were abused - I deal with both issues from the early abuse and issues re: the brain injury.
79 My husband and I have a real sense of family.
79 We just try and keep plugging away.
80 I've kept an open mind - at first I was upset by his suicide threats and possibility of starting to use drugs- but that has been resolved.
80 We opened the communication channels - we communiate with each other - as soon as we started talking again it helped.
80 He contacted the insurance company and got help-He saw a psychologist.
81 I've talked to doctors - family physician, psychologist, and specialist.
81 I've talked to friends.
81 We have friends who take us out.
82 I walk a lot.
83 I do a lot of praying
83 I go to church.
83 I walk away, ignore his behavior, because reasoning doesn't work.
83 I've built a wall and so have the kids - it's like teflon to protect us from his anger.
83 Sometimes I go for a drive to get peace of mind.
84 I adjust myself to his moods, I leave him alone if he's cranky.
84 I don't think about it.
84 I talk with my friends.
84 I try to stay calm.

Additional comments which did not address the questions asked

03 Doctors are terrible.
03 Information was not available.
18 Hard to put the feelings into words.
19 The system doesn't help the relative.
20 Others would say how amazing I am and how incredible I am to cope with this - but I don't feel that way.
24 A lot of anger - I haven't dealt with it in many ways.
30 I couldn't afford counselling.
34 It really happened to both of us.
57 He doesn't dwell on it, give up, he's fought it all the way.
66 In the beginning it was easier but it has become more difficult over time because at first I was able to attribute his words and actions to him being hurt or in pain, but now I can't.
68 We have a pretty close relationship.
70 Everyone puts you on hold for the first year until they see if you "heal" or not and he needed help most in the first year.
70 The system doesn't focus on strengths but rather the injured person must fail first and then they get help e.g., insurance wants to focus on the negative.

APPENDIX E

First Sort of Statements Generated by the Two Open-Ended Questions

Question 1. Please list the ways (positive or negative) in which your husband's brain injury has affected you.

Positive Themes

A - home more
B - less shy
C - more patience
D - more closeness
E - life is more precious
F - more independent
G - care more about him and others/glad he's alive
H - more strength
I - change attitude
J - more confidence
K - more assertiveness
L - support by others
M - return to work or school
N - more mature
O - better person
P - increased faith
R - survivor
S - accomplishment
T - changed life for better
U - self growth
V - more capable
W - more compassion for others

A01 Husband is at home more and I enjoy his company.
B02 I'm no longer shy and withdrawn. It brought me out of my shell.
B30 Before the accident he was head of the household and I was a shy person with a poor self-image and lots of fears. I underfunctioned in the relationship and he overfunctioned.
C05 I developed the patience of Job - although I think I've lost some of it the past couple of years.
C26 It's made us more patient.
D05 We're closer because we're so open about it.
D06 Brought family even closer together.
D08 We are closer as a family.
D26 It's made us closer.
D70 It has made us much closer as a family.
E08 Life is more precious.
E13 I had to re-examine the whole relationship and decide which things were important to me. I've gained a better understanding of what's important to me.
E26 It's made us more aware of a lot of things - what's important.
E31 It's made me appreciate him and our family more.
E64 It's made me more appreciative.
E64 It's made me more aware of life itself.
F14 Made me more independent.
F52 In some ways it's made me a more independent and stronger person.
G07 I became very protective of him, watchful.
G08 I care about him more than before.
G15 At first it was definitely negative, now I'm looking at it as positive, we've still got him.
G26 What kept us going is knowing how lucky we are that he turned out so well.
G34 I'm grateful he's here.
G68 I became a more caring person.

G68 I don't take him for granted anymore.
G68 It made me realize how much I do care for him.
H02 My family depend on me.
H12 Had to be stronger.
H14 It toughened me up.
H14 You have to cope with things, you stick by.
H15 I found strength after this, I had it all along but never used it.
H26 It's made me a lot stronger.
H29 Out of it all I became a very much stronger person - but I think there are easier ways to grow!
H30 I have become much stronger.
H30 While he was in hospital I had to stand on my own feet and the surprise was that I could do it.
H31 Emotionally it has made me stronger.
H31 I had to handle everything myself and I was successful.
H64 It's made me a lot stronger.
I28 It changed my attitude toward people with injuries.
J31 It has given me more confidence in myself.
K05 I became more assertive.
L27 Family and friends rallied to support us, people were kind to us.
L31 All the churches prayed for us.
L31 It's helped me to appreciate my small town because we've lived here a long time and people stood behind us - there was strong support.
M29 A plus was that it made me go back to school.
N31 It has made me mature.
N55 For the first little while it made me grow up more.
O64 It made me a better person.
P68 I've come to know the Lord in this time.
R05 I became a survivor.
S04 Pride in knowing you did your very best for someone you love.
T01 Better - changed life.
U77 I grew, I do things I didn't think I could do.
V77 Now I know what I'm capable of.
W29 I've become very compassionate to others i.e., any survivors.
W68 I have more compassion for others.
W70 I have more compassion for people, especially regarding people involved with impaired drivers.
W78 I'm more tolerant/understanding of people with disabilities in general.

<u>Negative Themes</u>

Aa - change in lifestyle
Ab - increased stress
Ac - increased negative feelings in general
Ad - increased dissatisfaction with relationship
B - decreased social contact
C - hard on children/change in relationship with children
D - change in emotionality, more aggressive, angry, easily upset, nervous, depressed, etc.
E - lack of support
F - more responsibilities
G - no father
H - more guilt
Ia - more decisions
Ib - decreased memory
Ic - decreased cognitive ability
J - decreased finances
K - his being home is difficult
L - decreased sex life
Ma - decreased physical capabilities
Mb - decrease or change in activities

N - he's self centered/demands attention
O - other change in husband
P - change in personality
Q - role reversal
R - increased worry
S - increased dependency by husband/need to spend more time with him
Tb - change in spousal relationship
Tc - husband childlike or childish
U - woman needs patience
V - woman hurts to see him like this
W - woman tired
X - woman changed
Y - focus in life becomes brain injury
Z - stress because others don't see the changes

Aa01 It's a whole new ballgame - life is very stressful.
Aa03 Disrupted whole life.
Aa06 Lots of stress.
Aa08 Mentally/emotionally drained many times because of his frustration (not able to move around, attend choir).
Aa10 Changed our lifestyle.
Aa10 It's changed our way of life.
Aa10 We just can't get up and go and do things.
Aa14 More stress.
Aa17 The last year has been really rough.
Aa19 I can understand how men feel frustrated being the head of the household.
Aa24 A lack of direction for the future because of his lack of direction.
Aa28 There was a change in lifestyle at first. He was in hospital for 4 months.
Aa31 We did struggle.
Aa33 We don't travel much anymore. Our lifestyle that was has changed. We used to travel to southern and northern Alberta and Saskatchewan to visit family.
Aa37 I watch what I cook in order to prevent a heart attack.
Aa45 It's been difficult.
Aa50 Everything changes so much.
Aa51 We've had to change our whole way of living - socially, mentally.
Aa56 Before this happened I was ready to update my education but then it happened and I couldn't.
Aa56 It's changed our lives completely.
Aa57 I go to work and come home and there is not much difference (I work in a hospital).
Aa58 I can't do the things I want because I have to stay home.
Aa64 It's changed my life totally.
Aa73 The first year was the hardest because of the loss of security.
Aa74 I'm alone a lot now.
Aa74 We don't socialize like we used to.
Aa74 We tend to do more socially with people he's known a long time to reduce the stress on him.
Aa75 I feel I don't have a life.
Aa75 It affected every way my life.
Aa76 Change in lifestyle.
Aa76 Our lives are so different than they used to be.
Ab03 Stress of having to take over the whole family.
Ab06 Too many demands on my time.
Ab18 Being at home can be very tense rather than relaxing.
Ab18 It's put a lot of pressure on me.
Ab24 Overall increase in stress level.
Ab27 It's been negative - a lot of work and strain.
Ab36 It is very stressful. There are a lot of worries and concerns and it's hard to take.
Ab41 I've had such a shock - it's thrown me.
Ab41 My world is just topsy turvy.

Ab42 Just the upset of it all, the trauma of it all, I was pregnant when it happened.
Ab56 There is a high stress factor.
Ab71 It's given me some really difficult times, worries, problems.
Ab73 In the first year there was a lot of mental and physical strain.
Ab76 A lot more strain, a lot more pressure.
Ab77 Sometimes it's just too much, sometimes I wish I could share everything with my husband.
Ab82 We've had a lot more stress.
Ac05 I need coping skills that I don't have.
Ac17 I haven't recovered yet.
Ac29 I lost my identity for a while. Life revolved around the family. It was very difficult to pull myself out of all of that.
Ac47 It's hard for me because I can't do anything to help him.
Ac49 At the beginning I had a lot of adjusting to do.
Ac56 I've given up a lot - I feel bitter about what I had to do - I don't like my work.
Ac74 I don't have time to myself anymore.
Ac74 I don't laugh like I used to do.
Ac74 I'm a lot more tense than I used to be but I haven't resorted to meds.
Ac74 I'm emotionally fatigued a lot.
Ac74 I'm tired a lot.
Ac83 I cry a lot.
Ad17 We don't see eye to eye.
Ad18 It is very hard to get along with him.
Ad23 There are some changes, irritating, but I live with them.
Ad23 Times where he just bugs me since the accident.
B01 Lost social contact.
B29 Social isolation.
B33 Socializing has decreased.
B35 He's very antisocial and he ignores my three children from my previous marriage.
B40 Our social life is not anything anymore.
B57 I've given up a lot, family-wise, in the past couple of years as he has trouble accepting my family.
B60 We lost a lot of friends.
C02 He will side with the children rather than discipline them.
C02 It's been hard on the children - especially our oldest daughter - especially when she can outsmart her father.
C04 Children lost their teen years and had to grow up too fast.
C17 I have be the referee between him and the kids.
C17 There are fights between the kids and him.
C19 I take care of the kids and until last year I couldn't leave them alone with him.
C27 It really negatively affected our 18-year-old son.
C31 It affected our young one who had a psychologist.
C35 Our 13-year-old won't bring friends home - it's really hard on him. They used to do so many things together.
C47 He's always angry at the kid.
C51 I couldn't give the kids the attention they needed.
C51 I have to be both mom and dad to the kids.
C51 The kids missed out on their dad.
C51 The kids suffered the worst.
C55 He can't put up with noise as much as before, therefore, I had to keep the kids quiet (they were young when this first happened).
C56 It's been very difficult for my daughter at home.
C60 It's been especially hard on the children, the children went through hell. I would like to see a program for the children.
C62 He doesn't remember where he puts things and then he blames the kids and he gets into a temper.
C73 In the first year I had to be mother and father to the kids.
C83 He can't show the kids love.
D03 Mental abuse (not physical).

D04 He was very abusive both verbally and physically.
D05 He became more aggressive.
D07 He's had mood swings.
D18 He gets mad or loses his temper with our 3-year-old son but at this point there does not seem to be much effect on our son.
D21 It's a real strain because he gets mad easy over anything - any little thing.
D22 He has violent outbursts.
D22 His emotions are at the surface, therefore, we have to deal with him - tippie toe.
D31 He suffers from depression.
D35 He doesn't care where he pulls a temper tantrum - which creates a lot of embarrassment.
D35 He gets aggressive very quickly - he has a very bad temper.
D42 We're (the family) more careful not to upset him.
D46 He gets frustrated easily and his temper is uncontrollable at times.
D47 He's frustrated.s mood swings.
D48 He has mood swings - which cause stress for me.
D48 His temper, he's not the same - he gets emotional fast.
D49 He gets very angry over the least little things.
D49 He is very unhappy.
D51 Emotionally he can't go to social functions, so I have to go by myself to things like weddings and funerals.
D54 Sometimes he gets quick tempered and pushes or shoves me.
D60 It's a lot of strain with his temperament. I know when to talk and when not to talk.
D62 When he gets angry I have to keep quiet.
D63 His anger gets out of control.
D64 It was really very scary at the beginning. He was very aggressive and we were afraid that he would stay that way. He said everything and anything.
D66 What was affected was his inability to control his emotions.
D69 He gets angry.
D69 He gets very nervous - fast.
D71 He gets deeply depressed and thinks things that aren't true.
D72 Mood changes - he gets depressed easily.
D73 The first year was the hardest because of the unsureness of what would happen because of his temper swings.
D79 He used to be quiet and nice, now he's angry and nobody can do anything right.
D80 Emotionally speaking it would really upset me because he would be screaming and yelling at me and the kids, my nerves were getting wrecked.
D81 He gets very frustrated and angry and then he gets irritated if I try to help him.
D82 He's quite nervous.
D83 He can't be "caring" - he thinks it's enough to support the family.
D83 He's angry all the time, and quick to anger - sometimes I'm afraid of his anger.
D83 He's mentally and verbally abusive (not physically) constantly.
E03 Lack of support medically and from social services.
E31 I was disappointed in the little support we received for the family from the hospital.
E34 I'm frustrated with the government and their lack of financial support/assistance.
E70 Doctors don't know how to help.
E70 I've had to fight to get documentation regarding areas he's not functioning in.
E70 There was incredible pressure for him to quit and stay home, therefore, he was penalized for wanting to keep going.
E73 I had no one to talk to, his family did not support me - they went against me.
E79 If he would have been alright when I got hurt I would have had some support.
F06 Totally responsible for his care.
F07 I had to take over all the responsibilities.
F08 As a result of the injury there are so many more responsibilities - I get drained.
F10 I have all of the responsibility.
F10 I have to do everything.
F12 Had to take control of everything.
F12 I have to do everything - pay bills, etc.
F12 Lots more responsibility.

F15 It's just my duty to take over responsibilities.
F19 All the heavy work is mine now
F21 I have to do more things and take over business responsibilities.
F24 Extra stress and responsibilities.
F28 It was very difficult to take care of everything by myself.
F29 It gave me so many new roles to play.
F31 The workload in the office was greater (owned a business)
F33 Before he had his driver's license I had a lot more responsibility - especially driving the kids around-this has changed now that he has his license.
F33 Before I worked for pleasure, now I work because I have to.
F34 Having to take control when I would rather have him do it.
F37 I do all his medical forms.
F40 I have to do most everything by myself. I never had to do that, he was the strong one.
F41 I've completely changed - having had to take charge.
F44 I've had to do all the driving.
F44 I've had to take charge of everything.
F50 I have more responsibility.
F51 I have total responsibility.
F55 The main thing was I had to do the driving.
F64 I take care of everything, I do it all.
F74 I have a lot more responsibility.
F77 My role changed, we used to share everything (duties, work, children), now everything is my responsibility.
F79 Mostly I've taken on most of his roles, everything was dumped on me.
F81 It's made me have to do everything, he doesn't drive, I'm the sole breadwinner, and he can't fix/repair things.
G06 He was unable to assume his role as a father
G16 Loss of father.
H06 Guilt for not being as good as one could.
H06 Lots of guilt especially regarding looking for fulltime placement for him now.
H66I 've dealt with a lot of guilt because I didn't like him anymore.
Ia07 I had to take over all the decisions.
Ia09 More decision making.
Ia10 I have to make most of the decisions.
Ia13 I had to make a lot of decisions and organize him - I did this longer than necessary.
Ia14 Take on all the decision making.
Ia19 All the worries about the future are mine now.
Ia19 He can't help me plan for the future.
Ia35 I hate making decisions, but I have to do it.
Ia35 Taking over major decision making. He's not capable of making a decision.
Ia40I have to make all the decisions by myself.
Ia42 I feel I have to listen and make sure he makes the right decisions.
Ia67 I will override my husband on decisions/actions re: the kids - I'll openly contradict him.
Ib22 He has no short term memory, therefore, things we may discuss and agree upon, he can't remember - creates a web of unhappiness.
Ib28 It took a long time for his memory to return.
Ib45 He has memory problems.
Ib72 I have to remind him more, he forgets easily. His memory is getting worse over time.
Ib73 In the first year him not remembering was very difficult.
Ib79 He gets angry at himself because he forgets things.
Ib79 Lots of things he used to do he doesn't remember to do.
Ib82 His memory is poor.
Ib84 He forgets everything.
Ic66 What was affected was his reasoning ability.
Ic76 He gets language and thoughts mixed up.
J16 Loss of income.
J22 Significant financial pressure.
J29 Financially.

J34 I'm frustrated that I can't provide for the family in the same way as he did.
J34 I'm frustrated with finances, not being able to pay bills and getting behind.
J37 I have to be more aware of financial things. He pays the bills but I have to monitor him.
J57 There has been financial stress.
J62 Finances are a problem.
J63 We have to keep ourselves on a budget.
J65 I have to monitor his finances or he'll spend the money without paying the bills.
K17 He has not been working and his being home all the time is difficult.
K30 He's home all the time and it's been a strain to get used to being under the same roof all the time.
L17 Not being able to have sex, no sex for a while, we're just not getting along.
L34 I'm frustrated sexually.
L79 Our sex life is down the tubes.
Ma19 His functioning is quite variable.
Ma22 He's tired, affected by the cold, and has seizures which all affect the family.
Ma81 He has poor balance and coordination and he suffers from bad headaches.
Ma84 He cannot hear too well-he cannot understand me.
Mb11 He leaves things sit for months.
Mb19 There are a lot of things he can't do physically.
Mb3[illegible] He's not able to work as he did before - he was very active in the community.
Mb33 Family activities have declined and are at a minimum.
Mb3[illegible] We were active in sports but now we don't play ball, ski, etc.
Mb45 He can't do what he did before.
Mb47He wishes he could do more stuff.
Mb49 He can't do things like cut the lawn, clean the sidewalk, etc.
Mb51 Everything we did before we couldn't do.
Mb51 He can't do any jobs like changing the oil.
Mb76 He has trouble travelling.
Mb81 Any little tasks we took for granted he can't do, for example, household and car repairs, even changing the oil, he did everything on the cars and now we have to hire someone to do these things.
Mb81 It's really changed us. We used to be very active with golf, curling, and fishing, but now he can't do anything anymore. He can only do a little gardening.
Mb83 I have to push him to get things done.
Mb83 I have to take money out of groceries to get things fixed.
N07 He's demanded a lot of my attention.
N19 He is self-centered.
N21 Everything has to be <u>his</u> way.
N45 He feels sorry for himself.
N83 Things have to be his way.
O07 He's had growing pains.
O07 He's had mood swings.
O11 He wants everyone to sympathize with him.
O11 He's too secretive with me - he does things behind my back.
O21 He complains that nobody talks to him or listens to him - his conversation is monotonous and perseverative.
O45 He's suicidal and homicidal
O45 My husband's psychological problems have increased dramatically since the accident.
O49 He doesn't sleep well.
O54 He's a bit slower at work.
P21 He's so totally out of character.
P30 In some ways he's different but in other ways he's the same but much more extreme - what has been heightened is frustrating for me (i.e., his worser qualities).
P34 He's not as easy going - so it's more stressful in dealing with him.
P46 He's just not the same person he was before.
P46 His personality isn't the same.
P48 He doesn't take the pressure as he used to.
P48 He is not the same person.

P49 His personality has changed completely.
P50 It's like dealing with a totally different person.
P52 He had a real personality change which has indirectly affected me.
P75 He's like a totally different person.
P76 Total change in his personality.
P82 He doesn't handle things as well as before.
P83 He overreacts to little things
P83 He's tight with money.
P83 He's very prejudiced - even more so than before his accident.
P83 I get blamed for everything.
Q28 There was a role reversal for about a year while he was at home all day.
R14 A lot more concern because I worry.
R31 I worry about him.
R36 I have had a lot of sleepless nights.
R37 I wonder if it's going to happen again. This creates stress. I am not as relaxed about things as before.
R53 Every now and then I worry about it and how it's affecting him.
R53 I worry about the soft spot in his skull.
R53 It's always there in the back of my mind.
R62 I worry a lot because he gets blackouts, especially when he's out alone.
R62 It's more stress on me, I worry a lot.
R81 I get nervous leaving him at home. He falls and I've had to take him to emergency three times because he poked his eye.
R81 I worry all the time.
R81 It's a constant worry, 24 hours a day.
R84 If he's sick it causes me a problem because I worry about what goes on in the house. I know he's not feeling good, he gets dizzy, and I'm worried he'll fall.
S09 He really relies on me now, he likes me to be there at all times.
S27 He's dependent.
S36 I have spent a lot of time with him.
S45 He relies on me more than he should.
S45 I've had to spend a lot of time with my husband.
S46 He depends on me more.
S60 I can't go out to work.
S60 I have to be with him constantly or else his mom and dad have to be with him.
S65 He seems to depend on me for everything.
S68 I was a little afraid that he was becoming too dependent on me but that has changed since he's been out of the hospital.
S79 I have to guide him through things he used to do on his own.
S81 I can't go away anywhere.
S81 I can't leave him alone.
Tb02 There has been trauma this past week as my husband has talked about wanting out of the marriage.
Tb06 He was unable to assume his role as a spouse.
Tb14 No one to discuss decisions with.
Tb16 Loss of husband.
Tb19 I don't have an equal partner because he can't make decisions or be supportive.
Tb24 It has affected how much I can rely on him - for example to take over the running of the household and manage with the three kids as he did before.
Tb27 The marriage has died.
Tb30 My newfound strength would have been welcomed before the accident but now he perceives it as negative because he sees himself as weaker.
Tb31 I had to stop mothering him.
Tb35 I miss him (she started to cry).
Tb37 I have to watch him regarding: cooking, mowing the lawn, etc.
Tb57 I want to get out of it but don't know how.
Tb57 It's caused wear and tear on our relationship.
Tb66 I lost my partner - I have more of a dependent.

Tb67 I used to be a lot more understanding of my husband.
Tb67 I used to give my husband more credit for being his own person.
Tb67 I worry more about our relationship.
Tb67 I'm a lot more judgmental of my husband.
Tb67 There was a time when I had no expectations of my husband, now I have a lot more.
Tb75 It affected me emotionally - there is no more affection between my husband and myself, no more love, everything is gone.
Tb83 It feels as though I'm between the kids and him.
Tc07 I've been torn between attending to him or to the children.
Tc07 It is like having two teens in the house.
Tc22 My relationship has become maternal - I have three sons instead of two.
Tc27 He's like another child.
Tc46 I get frustrated with him a lot - he's childish at times.
Tc50 It was like babysitting at first.
Tc51 My husband became like a child.
Tc63 It's like having another kid in the house.
Tc66 In a sense I'm living with a perpetual teenager.
U08 A lot of patience is required. I have to find patience many times.
U10 I have to have more patience.
U36 It has taken a lot of understanding and patience.
U44 He's very dependent on me.
U44 I've had to really counsel myself to have patience with him.
U50 I have to have lots of patience.
U69 I need a lot of patience for him.
V31 It hurts to see him going through this.
V68 It's been really hard watching someone I care about suffer and knowing that [illegible] was nothing I could do.
V70 It's been difficult watching someone I love struggle with self-esteem and self-concept.
V83 Emotionally it's really hard on the kids and it's hard for me to see this.
W57 I get tired.
X35 I feel resentment.
X41 I used to be bubbly/sparkly, but something "died" in me.
X49 I had a nervous breakdown 2 years ago.
X50 I have to be more organized.
X52 I've changed - I was very dependent on him before.
X66 I'm not as carefree or easygoing.
X66 I've become "hard" - as an insulation for myself so I don't get hurt by my husband's actions and words.
Y29 I began to live and breathe brain injury.
Y41 When one person in the house has a brain injury everyone has it.
Z70 My husband was high up professionally and he still functions extremely well but at a lower level for him and, therefore, others don't see the loss.
Z70 Others don't understand what he can or can't do e.g., his employers - his behavior appears inconsistent - and he finds that embarrassing and confusing and hard to explain.

Question 2. Please list the ways in which you have dealt with your husband's brain injury.

A - reading
a - hope
AA - laughter
B - support group for woman
b - work
BB - obtain information
C - friends
c - social worker
CC - not care

D - time away or retreat
d - give in/put up with
DD - neuropsychologist
E - children
e - tune out
EE - keep problems to self
F - move
f - adjust schedule/activities
FF - do things together
G - overlook things
g - keep journal
GG - cry
H - family support
h - push him to do things
HH - maintain normalcy/routine
I - volunteer work
i - crafts
II - give up things
J - take one day at a time
j - don't dwell on it
K - change expectations
k - medication for self
KK - walks
L - look for improvement
l - attend school
Ll - help or focus on others
LL - focus on self
M - be positive, make the best of it
m - keep kids quiet
N - physicians
n - adjust actions to his moods
O - assertiveness
o - talk to him/communicate
P - patience
p - group therapy for woman
Q - services (home care, cleaning lady)
q - leave him alone
R - sleep (for woman)
r - outside interests
S - faith/prayer
s - obtain funding/financial resources
T - psychologist (counselling)
t - ask for help
U - pace self
u - others support (work colleagues)
V - just do it/keep on going/deal with it/accept it
v - discipline or treat husband like a child
W - use common sense, logic
w - take over responsibilities
X - talk to others
Xx - self talk
x - praise him/help him/be there for him/support him/understand him/focus on him
Y - shop
y - live on acreage
Z - group therapy for husband
z - "wean" him gradually
ZZ - be objective

A 01 Reading.
A 02 Read.
A 30 I do a lot of reading. It helps keep me sane - I read especially on the topic of brain injury.
a 04 Hope that there would be help.
a 21 I just hope things will get better.
a 80 I've kept an open mind - at first I was upset by his suicide threats and possibility of starting to use drugs- but that has been resolved.
AA70 Teasing and joking about it works well for us as a family.
B 01 Support group was helpful but too short - people don't put time aside.
B 13 Belonged to a womens' support group in order to work through my own feelings
B 29 Began a brain injury support group for central Alberta.
B 29 I'm in the process of developing a support system to start in the emergency room.
B 60 It helped to have an informal support system with two other women whose husbands had had brain injuries.
b 16 Keeping on working.
b 18 I go to work.
b 21 I try to work extra hours if I can, just to get away.
b 22 I do more things that are work related e.g., conferences which don't include him and are a form of escape.
b [illegible]2 I spend more time at my job.
b [illegible]3 My work keeps me busy and active.
[illegible]1 I go to my job and get out of the house.
[illegible]8 I work
b 57 Going to work, it's my escape.
b 66 A job - I call it my "mental health" job.
b 75 I buried myself into my work.
BB02 I listen to a particular family program.
BB70 I've tried to be informed about injury - which areas have been affected.
BB73 I took it upon myself to go to the library and get information on brain injury.
BB77 Learning about it and having directions of what to do (from professionals) was helpful.
BB81 I've talked to doctors - family physician, psychologist, and specialist.
C 02 Contact with friends - time out with them. I have a close knit circle of friends.
C 14 When I get down I call my best girlfriend.
C 22 People don't really understand what happened, therefore, I don't count on old friends, so I've developed another support system - one good friend.
C 28 A friend volunteered to look after the kids.
C 30 A psychologist friend has been a good support to me.
C 33 I stuck it out with my friends - being able to talk to friends about it.
C 36 I have friends over.
C 46 I have friends I see.
C 49 I have good neighbours and friends.
C 73 I have a good girlfriend who listened and gave advice.
C 74 I try to once in a while get out with my own friends.
C 81 I've talked to friends.
C 81 We have friends who take us out.
C 84 I talks with my friends.
c 68 We saw a social worker for a while and may go back again.
CC71 I just couldn't care anymore.
CC71 I try not to get terribly depressed and not care as much.
D 02 Friday nights out.
D 22 My husband has become a recluse so I've become more outgoing in other areas of my life to compensate.
D 24 Retreated.
D 46 I curl.
D 46 I keep busy.
D 52 I keep busy and find things to do.
D 57 He does his thing, I do mine.
D 57 I don't sacrifice myself anymore.

D 57 I get away - to visit my daughter in Calgary.
D 57 My time is mine.
D 60 I go skiing with my daughter.
D 67 Sometimes we've stayed away from people in order to have time alone.
D 67 We go out and be a couple and have fun.
D 83 Sometimes I go for a drive to get peace of mind.
d 18 I put up with it.
d 22 I concede a lot of things because I can't follow it up - it upsets my husband too much.
d 54 I back down if there is an argument.
d 54 I watch what I say.
d 62 I don't say anything when he gets angry.
DD73 I kept in touch with the neuropsychologist.
E 02 Having three children after the injury helped me cope.
E 04 Kids feel where others fail it's because they don't involve the kids - the kids appreciated being involved.
E 04 Kids were and are a tremendous support for me.
E 26 Lucky to have the kids - they helped me and came through it as well as I did.
E 26 The kids handled it so well - it helped me.
E 44 My oldest son will call and come out and see me now, especially when I sound upset.
E 44 My three children were there at the time of the accident and provided support.
E 51 My son has provided tremendous support - he stays with me half time.
E 52 The kids have been a wonderful form of support.
E 65 I get support from my eldest daughter and grandchildren.
E 75 Children provided support that I didn't get anywhere else.
E 75 If I didn't have the children I don't think I would have survived.
e 23 Sometimes I just tune him out.
e 46 I try to ignore a lot of things going on - put them out of my mind.
e 66 I've insulated myself against him.
e 83 I walk away, ignore his behavior, because reasoning doesn't work.
e 83 I've built a wall and so have the kids - it's like teflon to protect us from his anger.
EE18 I don't want to put negative feelings against my husband with my family so I don't talk about it with them.
EE7[illegible] try to keep problems to myself.
F 02 Moving to a smaller town was helpful.
F 22 We moved back to the city to facilitate my employment and better medical attention for my husband, and he's improved greatly since we moved.
F 54 We moved out of the city - he feels more protected because tornados don't like trees.
f 24 I have adjusted time schedules, personal and family in order to accommodate the changes.
f 24 I have dropped activities that I may have done before - extracurricular things - clubs, community organizations, school things.
f 51 I've changed a lot of my entertainment e.g. We used to [illegible] and have friends over but we can't do that now. We also used to curl and golf but now [illegible] go out camping with the kids and play cards.
f 56 I've learned to adjust myself to his moods.
f 56 It required a total readjustment of my life.
f68 I spent a lot of time at the hospital.
FF74 We try to do things socially together-like movies.
G 03 Overlooked many things - not his fault.
g 30 I keep a journal on the recommendation of my psychologist friend.
GG75 I cried a lot.
H 03 Family support.
H 14 When I get down I call my mother.
H 15 Everyone around me was supportive.
H 26 Lots of support among family members.
H 28 His relatives did little things to help like mow the lawn.
H 30 Family has been a big support.
H 36 I've had support from family.
H 49 I have a lovely little granddaughter.

H 53 Both sets of parents came to help originally.
H 68 My sister-in-law was there for me, she was someone to talk to.
H 77 It was important to stay together as a family.
H 79 My husband and I have a real sense of family.
h 35 I have to make him do things to keep his brain active.
h 50 He picked up bad habits e.g., watching T.V., and I had some problems to get him to go out and communicate with others.
h 50 I have to insist a lot, demand, push.
h 50 I have to let him try and learn or make him do it.
HH77 We tried to keep as normal a life as possible.
I 04 Becoming involved in volunteer work.
i 45 I've got more into doing crafts.
II60 I gave some land back so we could cope with it.
II71 I've given up things.
II77 We were able to give up things to cut back on finances.
J 04 Live day by day - not look to the future.
J 07 Day to day accept things.
J 32 I took one day at a time.
J 34 Take things a day at a time.
J 40 I take one day at a time.
J 41 I live one day at a time - some days are better than other days, depending on his moods.
J 48 I take things day by day.
J 49 I accept one day at a time.
J 60 Take one day at a time.
j 34 A lot of times I tend to forget about it.
j 34 I don't dwell on it.
j 48 I don't think back on the accident.
j 51 I try not to dwell on the accident and to not use it as a crutch. I think I did for a while.
j 77 It helped to have little time to think and dwell on it
j 84 I don't think about it.
K 22 I was a perfectionist and had to change because he would never meet my standards. I changed my standards.
k 49 I use medications.
KK 44 I give myself time - time to myself to get away - I go for walks.
KK82 I walk a lot.
l 16 Going to university.
l 29 I went back to school, took upgrading, became a psychiatric nurse.
l 52 I took RN training as a way of dealing with it. I had trouble being dependent on the government for a living. RN training was an escape route.
LI04 Trying to help others.
LI77 In many ways I was too busy to help myself - I concentrated on my daughter and husband.
M 04 Being positive.
M 04 Look for any little improvement.
M 04 Look for the good that happened that day.
M 10 Being very positive.
M 10 We make the best of it.
M 34 Focus positively.
M 34 I'm grateful he's here.
M 34 Knowing how fast time goes by.
M 34 Try not to be bitter or selfish - I put myself in his shoes and see it from his point of view.
M34 I would never consider leaving him.
M 40 I'm grateful for every little improvement.
M 51 I do the best I can.
M 52 I have a really positive attitude - today may be bad but tomorrow will probably be better.
M 77 I tried to keep my spirits up.
M 79 I love my husband and don't want our marriage to end - the fact that we care about each other keeps us together.
m 55 It was just minor brain damage so I just had to keep the kids quiet - noise distracted him.

N 05 Taken him to various doctors and professionals.
N 14 I've talked to my doctor about it.
N 31 I talked to our family doctor.
N 49 My psychiatrist helped me a lot.
N 64 My husband had a wonderful doctor who brought me articles in the hospital.
N 73 We have a good family doctor who listened and gave advice.
N 77 I talked to a doctor.
n 56 I've learned to watch for the signals because there is that area of moods and mood swings - he's very unpredictable.
O 05 Assertiveness.
o 05 Very open about it - doesn't hide it.
o 45 I've tried to sit back and talk to him - try to help him remember things.
o 50 When he becomes frustrated I sit down and have discussions with him.
o 67 Communication is the biggest thing.
o 67 Everyday we sit down and talk about how we're feeling.
o 67 It takes more work to work things out.
o 68 Being able to talk to my husband, about what was happening, helped.
o 70 As a family we're extremely open about talking and laughing about it (the brain injury).
o 72 We talk about it-we have good communication.
o 80 We opened the communication channels - we communiate with each other - as soon as we started talking again it helped.
P 05 Patience.
P 50 I had a lot of patience.
P 69 I use patience, lots of patience.
P 84 I try to stay calm.
p 30 I took a caregivers class at the Glenrose.
p 65 I attend the caregivers group at the Glenrose.
p 79 I'm in a support group for people who were abused - I deal with both issues from the early abuse and issues re: the brain injury.
Q 06 Had a cleaning lady for a while.
Q 06 Initially had homecare but don't want to go back to that because it's an intrusion.
q 07 Try not to put too much pressure on him - helped me recognize what he couldn't do.
q 47 I leave him alone - he seems to get better if no one is bothering him.
q 54 I don't bug him about things.
q 84 I adjust myself to his moods, I leave him alone if he's cranky.
R 05 Sometimes escape by going to sleep.
r 66 I have lots of outside interests. I do things on my own.
S 06 Christian faith.
S 08 Doing a lot of praying.
S 08 My faith keeps me going.
S 17 I go to church on a regular basis.
S 27 Our church and my faith.
S 29 Joined a church organization.
S 30 A whole lot of praying.
S 30 Church has been a big support. The church has also started a support group for dysfunctional families which I attend.
S 32 I prayed.
S 33 Church has supported us 100%, helped with the kids, helped spiritually.
S 65 I believe in God and I pray.
S 68 I did a lot of praying.
S 68 I found the Lord.
S 68 I get my strength from the Lord.
S 83 I do a lot of praying
S 83 I go to church.
s 06 Got funding.
s 27 I had the financial resources to make a go of things.
T 07 I send him to a psychologist.
T 17 Career Connectors in our small town have given me some help.

T 17 I tried to get counselling through Family and Social Services but have been unable to due to limited resources in small community.
T 19 My husband and I see a psychologist.
T 21 We did see a psychologist, but it was more for my husband.
T 24 Counselling.
T 27 I saw a psychologist at NABIS and had a one hour session with her which I found very helpful.
T 31 My husband did go for therapy but his psychologist couldn't give me information for me to help him.
T 49 My husband attends counselling.
T 54 We sought marital counselling.
T 63 We're getting family counselling - my son was hurt as well.
T 67 He saw a psychologist.
T 67 I saw a psychologist - just a couple of times.
T 72 I attend counselling - a company rep. comes out to the house and provides counselling.
T 75 I had counselling help.
T 76 We see a counsellor.
T 77 I talked to a counsellor at a rehab centre.
T 79 I'm getting counselling.
T 80 He contacted the insurance company and got help-He saw a psychologist.
t 28I had to overcome my belief that I could "do it all".
t 28 Initially difficult because I didn't want to ask for help.
u 33 My husband's company has been ace - drove him to and from the Glenrose and invites us to company functions.
U06 Learning to pace myself - key thing.
V 02 I had to manage.
V 03 Just deal with it.
V 06 Accept they (the family) can't do everything.
V 07 I keep accepting the way his is.
V 08 Just keep on going.
V 08 You have the strength when you have to do it.
V 10 Life has to go on.
V 13 Take charge.
V 15 I've learned to cope with it.
V 15 I've learned to live with it.
V 19 Find a solution and go ahead and do it, cope, deal with it.
V 19 I am not a quitter.
V 19 My general attitude is, this is the problem so let's find a solution.
V 26 Accepting that it happened and accepting that the changes in him are permanent and then just going on.
V 26 After a year we went back to the university (hospital) and it was then that we accepted that is how he is going to be.
V 26 Big change in everyone's life and just need to keep fighting and moving forward.
V 26 Need to just keep fighting and going on.
V 34 I can love any changes in him.
V 34 I don't expect things to be the same.
V 34 I'm willing to accept him.
V 34 The more time goes by the more I accept how things are, things are improving.
V 34 We've been together half my life, he's part of me, anything that happens I can accept.
V 36 I've had to accept it - that makes it easier.
V 40 I won't give up.
V 42 At first I had unrealistic expectations, but now I don't.
V 42 I don't get upset at his outbursts, I just accept them as part of his injury.
V 49 I accept what happens.
V 51 I have to live with it.
V 51 I just went on with life.
V 51 Life goes on.
V 53J ust carried on.
V 56 I deal with it as it happens and does not happen.

V 60We've gotten used to it.
V 64 I do what I have to do.
V 79 We just try and keep plugging away.
v 23 Sometimes he's like a teenager and I deal with him as I would my teenage sons.
v 35 I had to learn to put my foot down, to be firm with him, sometimes I treat him like a kid, and even yell at him. (At first I had let him make financial decisions and we got further and further into debt.)
W 05 I'm a very logical thinker, which was positive.
W 12 Common sense.
w 24 I have taken on the required responsibilities.
w 56 I had to assume all responsibility.
X 13 I talked to people at the hospital re: what was happening - in order to feel in control.
X 15 Talked about it.
x 07 Try to understand.
x 13 When my husband was in the hospital I wasn't a passive observer. I was active in his recovery. I spent hours with him.
x 35 I have to keep praising him.
x 47 I try to be there when he needs me.
x 47 I try to help him out as much as I can.
x 50 I had to simplify a lot of things for him - to explain routines - because his logic was screwed up. He would go from a to c and miss b.
x 53 I was very supportive of him - he was worried about the hole in his head.
x 54 I want to help him if I can rather than leave him.
x 60 I can calm him down.
x 74 I just really tried to stand by him.
x 74 I try not to make him dependent.
x 74 I try to reduce the stress on him.
x49 I've done a lot of talking to myself - to cope and not get annoyed with myself.
4 I go on a little shopping spree - it's just a little lift.
I think it helps a lot to be on an acreage.
06 Get the help that is helpful to my husband.
Z 09 Gone to NABIS
Z 16 NABIS to a small degree.
Z 19 At the time of the accident it was hard to get information and so I had to get it myself.
Z 19 I find resources for the problems.
Z 19 My husband goes to two anger clinics.
Z 19 My husband goes to a relaxation clinic to learn how to deal with anxiety.
Z 26 I went to a NABIS meeting when I was at a low ebb and came out feeling sorry for everyone else who seemed worse off than me.
Z 63 Being at the Glenrose.
Z 67 He took a stress management course twice and I took the second course with him.
Z 70 We're very aware of support groups but don't use them - my husband finds them too negative.
z 44 I need to wean him (from me) - he's very demanding.
ZZ76 Trying not to get frustrated - step back from the situation when things occur.

APPENDIX F

Second Set of Statements Generated by the Two Open-Ended Questions

Question 1. Please list the ways (positive or negative) in which your husband's brain injury has affected you.

<u>Positive Themes</u>

A - home more
B - less shy
C - more patience
D - more closeness
E - life is more precious
F - more independent
G - care more about him/glad he's alive/protective of him
H - more strength
I - change attitude
J - more confidence
K - more assertiveness
L - support by others
M - return to work or school
N - more mature
O - better person
P - increased faith
R - I became a survivor
S - proud of accomplishment
T - changed life for better
U - self growth
V - more capable
W - more compassion for others

1. positive changes in the woman (categories B, C, F, H, J, K, N, O, P, R, U, V, W)

2. positive changes in the relationship (family/husband) (categories A, D, G)

3. positive changes in lifestyle (i.e., return to work or school) (categories M, T)

4. support from others (category L)

5. changes in perspective on life/people with disabilities (categories E, I)

1. Positive changes in the woman.

B02 I'm no longer shy and withdrawn. It brought me out of my shell.
B30 Before the accident he was head of the household and I was a shy person with a poor self-image and lots of fears. I underfunctioned in the relationship and he overfunctioned.
C05 I developed the patience of Job - although I think I've lost some of it the past couple of years.
C26 It's made us more patient.
F14 Made me more independent.
F52 In some ways it's made me a more independent and stronger person.
H02 My family depend on me.
H12 Had to be stronger.
H14 It toughened me up
H14 You have to cope with things, you stick by.
H15 I found strength after this, I had it all along but never used it.

H26 It's made me a lot stronger.
H29 Out of it all I became a very much stronger person - but I think there are easier ways to grow!
H30 I have become much stronger.
H30 While he was in hospital I had to stand on my own feet and the surprise was that I could do it.
H31 Emotionally it has made me stronger.
H31 I had to handle everything myself and I was successful.
H64 It's made me a lot stronger.
J31 It has given me more confidence in myself.
K05 I became more asse[illegible]
N31 It has made me matur[illegible]
N55 For the first little while it made me grow up more.
O64 It made me a better person.
P68 I've come to know the Lord in this time.
R05 I became a survivor.
S04 Pride in knowing you did your very best for someone you love.
U77 I grew, I do things I didn't think I could do.
V77 Now I know what I'm capable of.
W29 I've become very compassionate to others i.e., any survivors.
W68 I have more compassion for others.
W70 I have more compassion for people, especially regarding people involved with impaired drivers.
W78 I'm more tolerant/understanding of people with disabilities in general.

2. Positive changes in relationship with husband or with family as a whole.

A01 Husband is at home more and I enjoy his company.
D05 We're closer because we're so open about it.
D06 Brought family even closer together.
D08 We are closer as a family.
D26 It's made us closer.
D70 It has made us much closer as a family.
G07 I became very protective of him, watchful.
G08 I care about him more than before.
G15 At first it was definitely negative, now I'm looking at it as positive, we've still got him.
G26 What kept us going is knowing how lucky we are that he turned out so well.
G34 I'm grateful he's here.
G68 I became a more caring person.
G68 I don't take him for granted anymore.
G68 It made me realize how much I do care for him.

3. Positive change in lifestyle.

M29 A plus was that it made me go back to school.
T01 Better - changed life.

4. Support from others.

L27 Family and friends rallied to support us, people were kind to us.
L31 All the churches prayed for us.
L31 It's helped me to appreciate my small town because we've lived here long time and people stood behind us - there was strong support.

5. Changes in perspective on life/people with disabilities.

E08 Life is more precious.
E13 I had to re-examine the whole relationship and decide which things were important to me. I've gained a better understanding of what's important to me.
E26 It's made us more aware of a lot of things - what's important.
E31 It's made me appreciate him and our family more.
E64 It's made me more appreciative.
E64 It's made me more aware of life itself.
I28 It changed my attitude toward people with injuries.

<u>Negative Themes</u>

Aa - change in lifestyle
Ab - increased stress
Ac - increased negative feelings in general
Ad - increased dissatisfaction with relationship
B - decreased social contact
C - hard on children/change in relationship with children
D - change in emotionality, more aggressive, angry, easily upset, nervous, depressed, etc.
E - lack of support
F - more responsibilities
G - no father
H - more guilt
Ia - more decisions
Ib - decreased memory
Ic - decreased cognitive ability
J - decreased finances
K - his being home is difficult
L - decrease sex life
Ma - decrease physical capabilities
Mb - decrease or change in activities
N - he's self centered/demands attention
O - other change in husband
P - change in personality
Q - role reversal
R - increase worry
S - increase dependency by husband/need to spend more time with him
Tb - change in spousal relationship
Tc - husband childlike or childish
U - woman needs patience
V - woman hurts to see him like this
W - woman tired
X - woman changed
Y - focus in life becomes brain injury
Z - stress because others don't see the changes

1. Overall change in lifestyle (overall increase in stress and changes in social life, finances, and recreation) (categories Aa, B, J, K, Mb, Y)

2. Change in woman
    a) overall stress (categories Ab, Z)
    b) role - decisions, responsibilities (categories F, Ia, Q)
    c) feelings, attitudes, behaviors (categories Ac, H, R, U, V, W, X)

3. Change in man

a) rel. with children (categories C, G)
b) personality, emotional, cognitive, physical (categories D, Ib, Ic, Ma, N, O, P, S, Tc)

4. Change in relationship (marital, sexual) (categories Ad, L, Tb)

5. Lack of support (category E)

1. Overall change in lifestyle (overall increase in stress and changes in social life, finances and recreation)

Aa01 It's a whole new ballgame - life is very stressful.
Aa03 Disrupted whole life.
Aa06 Lots of stress.
Aa08 Mentally/emotionally drained many times because of his frustration (not able to move around, attend choir).
Aa10 Changed our lifestyle.
Aa10 It's changed our way of life.
Aa10 We just can't get up and go and do things.
Aa14 More stress.
Aa17 The last year has been really rough.
Aa19 I can understand how men feel frustrated being the head of the household.
Aa24 A lack of direction for the future because of his lack of direction.
Aa28 There was a change in lifestyle at first. He was in hospital for 4 months.
Aa31 We did struggle.
Aa33 We don't travel much anymore. Our lifestyle that was has changed. We used to travel to southern and northern Alberta and Saskatchewan to visit family.
Aa37 I watch what I cook in order to prevent a heart attack.
Aa45 It's been difficult.
Aa50 Everything changes so much.
Aa51 We've had to change our whole way of living - socially, mentally.
Aa56 Before this happened I was ready to update my education but then it happened and I couldn't.
Aa56 It's changed our lives completely.
Aa57 I go to work and come home and there is not much difference (I work in a hospital).
Aa58 I can't do things the way I want because I have to stay home.
Aa64 It's changed my life totally.
Aa73 The first year was the hardest because of the loss of security.
Aa74 I'm alone a lot now.
Aa74 We don't socialize like we used to.
Aa74 We tend to do more socially with people he's known a long time to reduce the stress on him.
Aa75 I feel I don't have a life.
Aa75 It affected every way my life.
Aa76 Change in lifestyle.
Aa76 Our lives are so different than they used to be.
B01 Lost social contact.
B29 Social isolation.
B33 Socializing has decreased.
B35 He's very antisocial and he ignores my three children from my previous marriage.
B40 Our social life is not anything anymore.
B57 I've given up a lot, family-wise, in the past couple of years as he has trouble accepting my family.
B60 We lost a lot of friends.
J16 Loss of income.
J22 Significant financial pressure.
J29 Financially.
J34 I'm frustrated that I can't provide for the family in the same way as he did.
J34 I'm frustrated with finances, not being able to pay bills and getting behind.
J37 I have to be more aware of financial things. He pays the bills but I have to monitor him.

J57 There has been financial stress.
J62 Finances are a problem.
J63 We have to keep ourselves on a budget.
J65 I have to monitor his finances or he'll spend the money without paying the bills.
K17 He has not been working and his being home all the time is difficult.
K30 He's home all the time and it's been a strain to get used to being under the same roof all the time.
Mb11 He leaves things sit for months.
Mb19 There are a lot of things he can't do physically.
Mb31 He's not able to work as he did before - he was very active in the community.
Mb33 Family activities have declined and are at a minimum.
Mb33 We were active in sports but now we don't play ball, ski, etc.
Mb45 He can't do what he did before.
Mb47 He wishes he could do more stuff.
Mb49 He can't do things like cut the lawn, clean the sidewalk, etc.
Mb51 Everything we did before we couldn't do.
Mb51 He can't do any jobs like changing the oil.
Mb76 He has trouble travelling.
Mb81 Any little tasks we took for granted he can't do, for example, household and car repairs, even changing the oil, he did everything on the cars and now we have to hire someone to do these things.
Mb81 It's really changed us. We used to be very active with golf, curling, and fishing, but now he can't do anything anymore. He can only do a little gardening.
Mb83 I have to push him to get things done.
Mb83 I have to take money out of groceries to get things fixed.
Y29 I began to live and breathe brain injury.
Y41 When one person in the house has a brain injury everyone has it.

2. Change in woman a) overall stress

Ab03 Stress of having to take over the whole family.
Ab06 Too many demands on my time.
Ab18 Being at home can be very tense rather than relaxing.
Ab18 It's put a lot of pressure on me.
Ab24 Overall increase in stress level.
Ab27 It's been negative - a lot of work and strain.
Ab36 It is very stressful. There are a lot of worries and concerns and it's hard to take.
Ab41 I've had such a shock - it's thrown me.
Ab41 My world is just topsy turvy.
Ab42 Just the upset of it all, the trauma of it all, I was pregnant when it happened.
Ab56 There is a high stress factor.
Ab71 It's given me some really difficult times, worries, problems.
Ab73 In the first year there was a lot of mental and physical strain.
Ab76 A lot more strain, a lot more pressure.
Ab77 Sometimes it's just too much, sometimes I wish I could share everything with my husband.
Ab82 We've had a lot more stress.
Z70 My husband was high up professionally and he still functions extremely well but at a lower level for him and, therefore, others don't see the loss.
Z70 Others don't understand what he can or can't do e.g., his employers - his behavior appears inconsistent - and he finds that embarrassing and confusing and hard to explain.

2. Change in woman b) role, decisions, responsibilities

F06 Totally responsible for his care.
F07 I had to take over all the responsibilities.
F08 As a result of the injury there are so many more responsibilities - I get drained.
F10 I have all of the responsibility.
F10 I have to do everything.

F12 Had to take control of everything.
F12 I have to do everything - pay bills, etc.
F12 Lots more responsibility.
F15 It's just my duty to take over responsibilities.
F19 All the heavy work is mine now
F21 I have to do more things and take over business responsibilities.
F24 Extra stress and responsibilities.
F28 It was very difficult to take care of everything by myself.
F29 It gave me so many new roles to play.
F31 The workload in the office was greater (owned a business)
F33 Before he had his driver's license I had a lot more responsibility - especially driving the kids around-this has changed now that he has his license.
F33 Before I worked for pleasure, now I work because I have to.
F34 Having to take control when I would rather have him do it.
F37 I do all his medical forms.
F40 I have to do most everything by myself. I never had to do that, he was the strong one.
F41 I've completely changed - having had to take charge.
F44 I've had to do all the driving.
F44 I've had to take charge of everything.
F50 I have more responsibility.
F51 I have total responsibility.
F55 The main thing was I had to do the driving.
F64 I take care of everything, I do it all.
F74 I have a lot more responsibility.
F77 My role changed, we used to share everything (duties, work, children), now everything is my responsibility.
F79 Mostly I've taken on most of his roles, everything was dumped on me.
F81 It's made me have to do everything, he doesn't drive, I'm the sole breadwinner, and he can't fix/repair things.
Ia07 I had to take over all the decisions.
Ia09 More decision making.
Ia10 I have to make most of the decisions.
Ia13 I had to make a lot of decisions and organize him - I did this longer than necessary.
Ia14 Take on all the decision making.
Ia19 All the worries about the future are mine now.
Ia19 He can't help me plan for the future.
Ia35 I hate making decisions, but I have to do it.
Ia35 Taking over major decision making. He's not capable of making a decision.
Ia40 I have to make all the decisions by myself.
Ia42 I feel I have to listen and make sure he makes the right decisions.
Ia67 I will override my husband on decisions/actions re: the kids - I'll openly contradict him.
Q28 There was a role reversal for about a year while he was at home all day.

2. Change in woman c) feelings, attitudes, behaviors

Ac05 I need coping skills that I don't have.
Ac17 I haven't recovered yet.
Ac29 I lost my identity for a while. Life revolved around the family. It was very difficult to pull myself out of all of that.
Ac47 It's hard for me because I can't do anything to help him.
Ac49 At the beginning I had a lot of adjusting to do.
Ac56 I've given up a lot - I feel bitter about what I had to do - I don't like my work.
Ac74 I don't have time to myself anymore.
Ac74 I don't laugh like I used to do.
Ac74 I'm a lot more tense than I used to be but I haven't resorted to meds.
Ac74 I'm emotionally fatigued a lot.
Ac74 I'm tired a lot.
Ac83 I cry a lot.

H06 Guilt for not being as good as one could.
H06 Lots of guilt especially regarding looking for fulltime placement for him now.
H66 I've dealt with a lot of guilt because I didn't like him anymore.
R14 A lot more concern because I worry.
R31 I worry about him.
R36 I have had a lot of sleepless nights.
R37 I wonder if it's going to happen again. This creates stress. I am not as relaxed about things as before.
R53 Every now and then I worry about it and how it's affecting him.
R53 I worry about the soft spot in his skull.
R53 It's always there in the back of my mind.
R62 I worry a lot because he gets blackouts, especially when he's out alone.
R62 It's more stress on me, I worry a lot.
R81 I get nervous leaving him at home. He falls and I've had to take him to emergency three times because he poked his eye.
R81 I worry all the time.
R81 It's a constant worry, 24 hours a day.
R84 If he's sick it causes me a problem because I worry about what goes on in the house. I know he's not feeling good, he gets dizzy, and I'm worried he'll fall.
U08 A lot of patience is required. I have to find patience many times.
U10 I have to have more patience.
U36 It has taken a lot of understanding and patience.
U44 He's very dependent on me.
U44 I've had to really counsel myself to have patience with him.
U50 I have to have lots of patience.
U69 I need a lot of patience for him.
V31 It hurts to see him going through this.
V68 It's been really hard watching someone I care about suffer and knowing there was nothing I could do.
V70 It's been difficult watching someone I love struggle with self-esteem and self-concept.
V83 Emotionally it's really hard on the kids and it's hard for me to see this.
W57 I get tired.
X35 I feel resentment.
X41 I used to be bubbly/sparkly, but something "died" in me.
X49 I had a nervous breakdown 2 years ago.
X50 I have to be more organized.
X52 I've changed - I was very dependent on him before.
X66 I'm not as carefree or easygoing.
X66 I've become "hard" - as an insulation for myself so I don't get hurt by my husband's actions and words.

3. Change in man a) rel. with children

C02 He will side with the children rather than discipline them.
C02 It's been hard on the children - especially our oldest daughter - especially when she can outsmart her father.
C04 Children lost their teen years and had to grow up too fast.
C17 I have be the referee between him and the kids.
C17 There are fights between the kids and him.
C19 I take care of the kids and until last year I couldn't leave them alone with him.
C27 It really negatively affected our 18-year-old son.
C31 It affected our young one who had a psychologist.
C35 Our 13-year-old won't bring friends home - it's really hard on him. They used to do so many things together.
C47 He's always angry at the kid.
C51 I couldn't give the kids the attention they needed.
C51 I have to be both mom and dad to the kids.
C51 The kids missed out on their dad.

C51 The kids suffered the worst.
C55 He can't put up with noise as much as before, therefore, I had to keep the kids quiet (they were young when this first happened).
C56 It's been very difficult for my daughter at home.
C60 It's been especially hard on the children, the children went through hell. I would like to see a program for the children.
C62 He doesn't remember where he puts things and then he blames the kids and he gets into a temper.
C73 In the first year I had to be mother and father to the kids.
C83 He can't show the kids love.
G06 He was unable to assume his role as a father
G16 Loss of father.

3. Change in man b) personality, emotional, cognitive, physical

D03 Mental abuse (not physical).
D04 He was very abusive both verbally and physically.
D05 He became more aggressive.
D07 He's had mood swings.
D18 He gets mad or loses his temper with our 3-year-old son but at this point there does not seem to be much effect on our son.
D21 It's a real strain because he gets mad easy over anything - any little thing.
D22 He has violent outbursts.
D22 His emotions are at the surface, therefore, we have to deal with him - tippie toe.
D31 He suffers from depression.
D35 He doesn't care where he pulls a temper tantrum - which creates a lot of embarrassment.
D35 He gets aggressive very quickly - he has a very bad temper.
D42 We're (the family) more careful not to upset him.
D46 He gets frustrated easily and his temper is uncontrollable at times.
D47 He's frustrated.
D47 He's not quite himself - he smood swings.
D48 He has mood swings - which cause stress for me.
D48 His temper, he's not the same - he gets emotional fast.
D49 He gets very angry over the least little things.
D49 He is very unhappy.
D51 He can't go to social functions, so I have to go by myself to things like weddings and funerals.
D54 Sometimes he gets quick tempered and pushes or shoves me.
D60 It's a lot of strain with his temperament. I know when to talk and when not to talk.
D62 When he gets angry I have to keep quiet.
D63 His anger gets out of control.
D64 It was really very scary at the beginning. He was very aggressive and we were afraid that he would stay that way. He said everything and anything.
D66 What was affected was his inability to control his emotions.
D69 He gets angry.
D69 He gets very nervous - fast.
D71 He gets deeply depressed and thinks things that aren't true.
D72 Mood changes - he gets depressed easily.
D73 The first year was the hardest because of the unsureness of what would happen because of his temper swings.
D79 He used to be quiet and nice, now he's angry and nobody can do anything right.
D80 Emotionally speaking it would really upset me because he would be screaming and yelling at me and the kids, my nerves were getting wrecked.
D81 He gets very frustrated and angry and then he gets irritated if I try to help him.
D82 He's quite nervous.
D83 He can't be "caring" - he thinks it's enough to support the family.
D83 He's angry all the time, and quick to anger - sometimes I'm afraid of his anger.
D83 He's mentally and verbally abusive (not physically) constantly.

Ib22 He has no short-term memory, therefore, things we may discuss and agree upon, he can't remember - creates a web of unhappiness.
Ib28 It took a long time for his memory to return.
Ib45 He has memory problems.
Ib72 I have to remind him more, he forgets easily. His memory is getting worse over time.
Ib73 In the first year him not remembering was very difficult.
Ib79 He gets angry at himself because he forgets things.
Ib79 Lots of things he used to do he doesn't remember to do.
Ib82 His memory is poor.
Ib84 He forgets everything.
Ic66 What was affected was his reasoning ability.
Ic76 He gets language and thoughts mixed up.
Ma19 His functioning is quite variable.
Ma22 He's tired, affected by the cold, and has seizures which all affect the family.
Ma81 He has poor balance and coordination and he suffers from bad headaches.
Ma84 He cannot hear too well-he cannot understand me.
N07 He's demanded a lot of my attention.
N19 He is self centered.
N21 Everything has to be his way.
N45 He feels sorry for himself.
N83 Things have to be his way.
O07 He's had growing pains.
O07 He's had mood swings.
O11 He's too secretive with me - he does things behind my back.
O11 He wants everyone to sympathize with him.
O21 He complains that nobody talks to him or listens to him - his conversation is monotonous and perseverative.
O45 He's suicidal and homicidal
O45 My husband's psychological problems have increased dramatically since the accident.
O49 He doesn't sleep well.
O54 He's a bit slower at work.
P21 He's so totally out of character.
P30 In some ways he's different but in other ways he's the same but much more extreme - what has been heightened is frustrating for me (i.e., his worser qualities).
P34 He's not as easy going - so it's more stressful in dealing with him.
P46 He's just not the same person he was before.
P46 His personality isn't the same.
P48 He doesn't take the pressure as he used to.
P48 He is not the same person.
P49 His personality has changed completely.
P50 It's like dealing with a totally different person.
P52 He had a real personality change which has indirectly affected me.
P75 He's like a totally different person.
P76 Total change in his personality.
P82 He doesn't handle things as well as before.
P83 He overreacts to little things
P83 He's tight with money.
P83 He's very prejudiced - even more so than before his accident.
P83 I get blamed for everything.
S09 He really relies on me now, he likes me to be there at all times.
S27 He's dependent.
S36 I have spent a lot of time with him.
S45 He relies on me more than he should.
S45 I've had to spend a lot of time with my husband.
S46 He depends on me more.
S60 I can't go out to work.
S60 I have to be with him constantly or else his mom and dad have to be with him.
S65 He seems to depend on me for everything.

S68 I was a little afraid that he was becoming too dependent on me but that has changed since he's been out of the hospital.
S79 I have to guide him through things he used to do on his own.
S81 I can't go away anywhere.
S81 I can't leave him alone.
Tc07 I've been torn between attending to him or to the children.
Tc07 It is like having two teens in the house.
Tc22 My relationship has become maternal - I have three sons instead of two.
Tc27 He's like another child.
Tc46 I get frustrated with him a lot - he's childish at times.
Tc50 It was like babysitting at first.
Tc51 My husband became like a child.
Tc63 It's like having another kid in the house.
Tc66 In a sense I'm living with a perpetual teenager.

4. Change in relationship (marital, sexual)

Ad17 We don't see eye to eye.
Ad18 It is very hard to get along with him.
Ad23 There are some changes, irritating, but I live with them.
Ad23 Times where he just bugs me since the accident.
L17 Not being able to have sex, no sex for a while, we're just not getting along
L34 I'm frustrated sexually.
L79 Our sex life is down the tubes.
Tb02 There has been trauma this past week as my husband has talked about wanting out of the marriage.
Tb06 He was unable to assume his role as a spouse.
Tb14 No one to discuss decisions with.
Tb16 Loss of husband.
Tb19 I don't have an equal partner because he can't make decisions or be supportive.
Tb24 It has affected how much I can rely on him - for example to take over the running of the household and manage with the three kids as he did before.
Tb27 The marriage has died.
Tb30 My newfound strength would have been welcomed before the accident but now he perceives it as negative because he sees himself as weaker.
Tb31 I had to stop mothering him.
Tb35 I miss him (she started to cry).
Tb37 I have to watch him regarding: cooking, mowing the lawn, etc.
Tb57 I want to get out of it but don't know how.
Tb57 It's caused wear and tear on our relationship.
Tb66 I lost my partner - I have more of a dependent.
Tb67 I used to be a lot more understanding of my husband.
Tb67 I used to give my husband more credit for being his own person.
Tb67 I worry more about our relationship.
Tb67 I'm a lot more judgmental of my husband.
Tb67 There was a time when I had no expectations of my husband, now I have a lot more.
Tb75 It affected me emotionally-there is no more affection between my husband and myself, no more love, everything is gone.
Tb83 It feels as though I'm between the kids and him.

5. Lack of support.

E03 Lack of support medically and from social services.
E31 I was disappointed in the little support we received for the family from the hospital.
E34 I'm frustrated with the government and their lack of financial support/assistance.
E70 Doctors don't know how to help.
E70 I've had to fight to get documentation regarding areas he's not functioning in.

E70 There was incredible pressure for him to quit and stay home, therefore, he was penalized for wanting to keep going.
E73 I had no one to talk to, his family did not support me - they went against me.
E79 If he would have been alright when I got hurt I would have had some support.

Question 2. Please list the ways in which you have dealt with your husband's brain injury.

A - reading
a - hope
AA - laughter
B - support group for woman
b - work
BB - obtain information
C - friends
c - social worker
CC - not care
D - time away or retreat
d - give in/put up with
DD - neuropsychologist
E - children
e - tune out
EE - keep problems to self
F - move
f - adjust schedule/activities
FF - do things together
G - overlook things
g - keep journal
GG - cry
H - family support
h - push him to do things
HH - maintain normalcy/routine
I - volunteer work
i - crafts
II - give up things
J - take one day at a time
j - don't dwell on it
K - change expectations
k - medication for self
KK - walks
L - look for improvement
l - attend school
Ll - help or focus on others
LL - focus on self
M - be positive, make the best of it
m - keep kids quiet
N - physicians
n - adjust actions to his moods
O - assertiveness
o - talk to him/communicate
P - patience
p - group therapy for woman
Q - services (home care, cleaning lady)
q - leave him alone
R - sleep (for woman)
r - outside interests
S - faith/prayer
s - obtain funding/financial resources
T - psychologist (counselling)

t - ask for help
U - pace self
u - others support (work colleagues)
V - just do it/keep on going/deal with it/accept it
v - discipline or treat husband like a child
W - use common sense, logic
w - take over responsibilities
X - talk to others
Xx - self talk
x - praise him/help him/be there for him/support him/understand him/focus on him
Y - shop
y - live on acreage
Z - group therapy for husband
z - "wean" him gradually
ZZ - be objective

1. Activity
    a. work/school (categories b, I, l)
    b. leisure/recreational (categories A, D, i, KK, r)
    c. other (categories g, R, Y)

2. Support
    a. social (categories C, E, H, X, u)
    b. professional
        i. individual (categories c, DD, N, T)
        ii. group (categories B, p, Z)
    c. other (categories Q, s)

3. Behaviors, thoughts, attitudes, outlooks
    a. positive (categories AA, a, BB, F, f, FF, G, GG, h, HH, j, J, K, L, Ll, LL, M, m, n, O, o, P, q, t, U, V, W, w, Xx, x, y, z, ZZ)
    b. negative (categories CC, d, e, EE, II, k, v)

4. Faith (category S)

1. Activity a) work/school (categories b, I, l)

b16 Keeping on working.
b18 I go to work.
b21 I try to work extra hours if I can, just to get away.
b22 I do more things that are work related e.g., conferences - which don't include him and are a form of escape.
b22 I spend more time at my job.
b33 My work keeps me busy and active.
b41 I go to my job and get out of the house.
b46 I work
b57 Going to work, it's my escape.
b66 A job - I call it my "mental health" job.
b75 I buried myself into work.
l04 Becoming involved in volunteer work.
l16 Going to university.
l29 I went back to school, took upgrading, became a psychiatric nurse.
l52 I took RN training as a way of dealing with it. I had trouble being dependent on the government for a living. RN training was an escape route.

1. Activity b) leisure/recreational (categories A, D, i, KK, r)

A01 Reading.

A02 Read.
A30 I do a lot of reading. It helps keep me sane - I read especially on the topic of brain injury.
D02 Friday nights out.
D22 My husband has become a recluse so I've become more outgoing in other areas of my life to compensate.
D24 Retreated.
D46 I curl.
D46 I keep busy.
D52 I keep busy and find things to do.
D57 He does his thing, I do mine.
D57 I don't sacrifice myself anymore.
D57 I get away - to visit my daughter in Calgary.
D57 My time is mine.
D60 I go skiing with my daughter.
D67 Sometimes we've stayed away from people in order to have time alone.
D67 We go out and be a couple and have fun.
D83 Sometimes I go for a drive to get peace of mind.
i45 I've got more into doing crafts.
KK44 I give myself time-time to myself to get away-I go for walks.
KK82 I walk a lot.
r66 I have lots of outside interests. I do things on my own.

1. Activity c) other (categories g, R, Y)

g30 I keep a journal on the recommendation of my psychologist friend.
R05 Sometimes escape by going to sleep.
Y14 I go on a little shopping spree - it's just a little lift.

2. Support a) social (categories C, E, H, u, X)

C02 Contact with friends - time out with them. I have a close knit circle of friends.
C14 When I get down I call my best girlfriend.
C22 People don't really understand what happened, therefore, I don't count on old friends, so I've developed another support system - one good friend.
C28 A friend volunteered to look after the kids.
C30 A psychologist friend has been a good support to me.
C33 I stuck it out with my friends - being able to talk to friends about it.
C36 I have friends over.
C46 I have friends I see.
C49 I have good neighbours and friends.
C73 I have a good girlfriend who listened and gave advice.
C74 I try to once in a while get out with my own friends.
C81 I've talked to friends.
C81 We have friends who take us out.
C84 I talks with my friends.
E02 Having three children after the injury helped me cope.
E04 Kids feel where others fail it's because they don't involve the kids - the kids appreciated being involved.
E04 Kids were and are a tremendous support for me.
E26 Lucky to have the kids - they helped me and came through it as well as I did.
E26 The kids handled it so well - it helped me.
E44 My oldest son will call and come out and see me now, especially when I sound upset.
E44 My three children were there at the time of the accident and provided support.
E51 My son has provided tremendous support - he stays with me half time.
E52 The kids have been a wonderful form of support.
E65 I get support from my eldest daughter and grandchildren.
E75 Children provided support that I didn't get anywhere else.
E75 If I didn't have the children I don't think I would have survived.

H03 Family support
H14 When I get down I call my mother.
H15 Everyone around me was supportive.
H26 Lots of support among family members.
H28 His relatives did little things to help like mow the lawn.
H30 Family has been a big support.
H36 I've had support from family.
H49 I have a lovely little granddaughter.
H53 Both sets of parents came to help originally.
H68 My sister-in-law was there for me, she was someone to talk to.
H77 It was important to stay together as a family.
H79 My husband and I have a real sense of family.
u33 My husband's company has been ace - drove him to and from the Glenrose and invites us to company functions.
X13 I talked to people at the hospital re: what was happening - in order to feel in control.
X15 Talked about it.

2. Support b) professional i) individual (categories c, DD, N, T)

c68 We saw a social worker for a while and may go back again.
DD73 I kept in touch with the neuropsychologist.
N05 Taken him to various doctors and professionals.
N14 I've talked to my doctor about it.
N31 I talked to our family doctor.
N49 My psychiatrist helped me a lot.
N64 My husband had a wonderful doctor who brought me articles in the hospital.
N73 We have a good family doctor who listened and gave advice.
N77 I talked to a doctor.
T07 I send him to a psychologist.
T17 Career Connectors in our small town have given me some help.
T17 I tried to get counselling through Family and Social Services but have been unable to due to limited resources in small community.
T19 My husband and I see a psychologist.
T21 We did see a psychologist, but it was more for my husband.
T24 Counselling.
T27 I saw a psychologist at NABIS and had a one hour session with her which I found very helpful.
T31 My husband did go for therapy but his psychologist couldn't give me information for me to help him.
T49 My husband attends counselling.
T54 We sought marital counselling.
T63 We're getting family counselling - my son was hurt as well.
T67 He saw a psychologist.
T67 I saw a psychologist - just a couple of times.
T72 I attend counselling - a company rep. comes out to the house and provides counselling.
T75 I had counselling help.
T76 We see a counsellor.
T77 I talked to a counsellor at a rehab centre.
T79 I'm getting counselling.
T80 He contacted the insurance company and got help-He saw a psychologist.

2. Support b) professional and non prof. ii) group (categories B, p, Z)

B01 Support group was helpful but too short - people don't put time aside.
B13 Belonged to a women's support group in order to work through my own feelings.
B29 Began a brain injury support group for central Alberta.
B29 I'm in the process of developing a support system to start in the emergency room.
B60 It helped to have an informal support system with two other women whose husbands had had brain injuries.

p3 0 I took a caregivers class at the Glenrose.
p65 I attend the caregivers group at the Glenrose
p79 I'm in a support group for people who were abused-I deal with both, issues from the early abuse and issues re: the brain injury.
Z06 Get the help that is helpful to my husband.
Z09 Gone to NABIS
Z16 NABIS to a small degree.
Z19 At the time of the accident it was hard to get information and so I had to get it myself
Z19 I find resources for the problems.
Z19 My husband goes to two anger clinics.
Z19 My husband goes to a relaxation clinic to learn how to deal with anxiety.
Z26 I went to a NABIS meeting when I was at a low ebo and came out feeling sorry for everyone else who seemed worse off than me.
Z63 Being at the Glenrose.
Z67 He took a stress management course twice and I took the second course with him.
Z70 We're very aware of support groups but don't use them-my husband finds them too negative.

2. Support c) other (categories Q, s)

Q06 Had a cleaning lady for a while.
Q06 Initially had homecare but don't want to go back to that because it's an intrusion.
s06 Got funding.
s27 I had the financial resources to make a go of things.

3. Behavior, thought, attitude, outlook a) positive (categories AA, a, BB, F, f, FF, G, GG, h, HH, j, J, K, L, Ll, LL, M, m, n, O, o, P, q, t, U, V, W, w, Xx, x, y, z, ZZ)

a 04 Hope that there would be help.
a 21 I just hope things will get better.
a 80 I've kept an open mind-at first I was upset by his suicide threats and possibility of starting to use drugs-but that has been resolved.
AA70 Teasing and joking about it works well for us as a family.
BB02 I listen to a particular family program.
BB70 I've tried to be informed about injury - which areas have been affected.
BB73 I took it upon myself to go to the library and get information on brain injury.
BB77 Learning about it and having directions of what to do (from professionals) was helpful.
BB81 I've talked to doctors - family physician, psychologist, and specialist.
F 02 Moving to a smaller town was helpful.
F 22 We move back to the city to facilitate my employment and better medical attention for my husband, and he's improved greatly since we moved.
F 54 We moved out of the city - he feels more protected because tornados don't like trees.
f 24 I have adjusted time schedules, personal and family in order to accommodate the changes.
f 24 I have dropped activities that I may have done before - extracurricular things - clubs, community organizations, school things.
f 51 I've changed a lot of my entertainment e.g., We used to dine out and have friends over but we can't do that now. We also used to curl and golf but now I go out camping with the kids and play cards.
f 56 I've learned to adjust myself to his moods.
f 56 It required a total readjustment of my life.
f68 I spent a lot of time at the hospital.
FF74 We try to do things socially together-like movies.
G 03 Overlooked many things - not his fault.
GG75 I cried a lot.
h 35 I have to make him do things to keep his brain active.
h 50 He picked up bad habits e.g., watching T.V., and I had some problems to get him to go out and communicate with others.
h 50 I have to insist a lot, demand, push.
h 50 I have to let him try and learn or make him do it

HH77 We tried to keep as normal a life as possible.
J 04 Live day by day - not look to the future.
J 07 Day to day accept things.
J 32 I took one day at a time.
J 34 Take things a day at a time.
J 40 I take one day at a time.
J 41 I live one day at a time - some days are better than other days, depending on his moods
J 48 I take things day by day.
J 49 I accept one day at a time.
J 60 Take one day at a time.
j 34 A lot of times I tend to forget about it.
j 34 I don't dwell on it.
j 48 I don't think back on the accident.
j 51 I try not to dwell on the accident and to not use it as a crutch. I think I did for a while.
j 77 It helped to have little time to think and dwell on it.
j 84 I don't think about it.
K 22 I was a perfectionist and had to change because he would never meet my standards. I
changed my standards.
LI04Trying to help others.
LI77 In many ways I was too busy to help myself-I concentrated on my daughter and husband.
M 04 Being positive.
M 04 Look for any little improvement.
M 04 Look for the good that happened that day.
M 10 Being very positive.
M 10 We make the best of it.
M 34 Focus positively.
M 34 I'm grateful he's here.
M 34 Knowing how fast time goes by.
M 34 Try not to be bitter or selfish - I put myself in his shoes and see it from his point of view.
M34 I would never consider leaving him.
M 40 I'm grateful for every little improvement.
M 51 I do the best I can.
M 52 I have a really positive attitude - today may be bad but tomorrow will probably be better.
M 77 I tried to keep my spirits up.
M 79 I love my husband and don't want our marriage to end-the fact that we care about each other
keeps us together.
m 55 It was just minor brain damage so I just had to keep the kids quiet - noise distracted him.
n 56 I've learned to watch for the signals because there is that area of moods and mood swings -
he's very unpredictable.
O 05 Assertiveness.
o 05 Very open about it - doesn't hide it.
o 45 I've tried to sit back and talk to him - try to help him remember things.
o 50 When he becomes frustrated I sit down and have discussions with him.
o 67 Communication is the biggest thing.
o 67 Everyday we sit down and talk about how we're feeling.
o 67 It takes more work to work things out.
o 68 Being able to talk to my husband, about what was happening, helped.
o 70 As a family we're extremely open about talking and laughing about it (the brain injury).
o 72 We talk about it-we have good communication.
o 80 We opened the communication channels - we communiate with each other - as soon as we
started talking again it helped.
P 05 Patience.
P 50 I had a lot of patience.
P 69 I use patience, lots of patience.
P 84 I try to stay calm.
q 07 Try not to put too much pressure on him - helped me recognize what he couldn't do.
q 47 I leave him alone - he seems to get better if no one is bothering him.
q 54 I don't bug him about things.

q 84 I adjust myself to his moods, I leave him alone if he's cranky.
t 28 I had to overcome my belief that I could "do it all".
t 28 Initially difficult because I didn't want to ask for help.
U 06 Learning to pace myself - key thing.
V 02 I had to manage.
V 03 Just deal with it.
V 06 Accept they (the family) can't do everything.
V 07 I keep accepting the way his is.
V 08 Just keep on going.
V 08 You have the strength when you have to do it.
V 10 Life has to go on.
V 13 Take charge.
V 15 I've learned to cope with it.
V 15 I've learned to live with it.
V 19 Find a solution and go ahead and do it, cope, deal with it.
V 19 I am not a quitter.
V 19 My general attitude is, this is the problem so let's find a solution.
V 26 Accepting that it happened and accepting that the changes in him are permanent and then just going on.
V 26 After a year we went back to the university (hospital) and it was then that we accepted that is how he is going to be.
V 26 Big change in everyone's life and just need to keep fighting and moving forward.
V 26 Need to just keep fighting and going on.
V 34 I can love any changes in him.
V 34 I don't expect things to be the same.
V 34 I'm willing to accept him.
V 34 The more time goes by the more I accept how things are, things are improving.
V 34 We've been together half my life, he's part of me, anything that happens I can accept.
V 36 I've had to accept it - that makes it easier.
V 40 I won't give up.
V 42 At first I had unrealistic expectations, but now I don't.
V 42 I don't get upset at his outbursts, I just accept them as part of his injury.
V 49 I accept what happens.
V 51 I have to live with it.
V 51 I just went on with life.
V 51 Life goes on.
V 53 Just carried on.
V 56 I deal with it as it happens and does not happen.
V 60 We've gotten used to it.
V 64 I do what I have to do.
V 79 We just try and keep plugging away.
W 05 I'm a very logical thinker, which was positive.
W 12 Common sense.
w 24 I have taken on the required responsibilities.
w 56 I had to assume all responsibility.
x 07 Try to understand.
x 13 When my husband was in the hospital I wasn't a passive observer. I was active in his recovery. I spent hours with him.
x 35 I have to keep praising him.
x 47 I try to be there when he needs me.
x 47 I try to help him out as much as I can.
x 50 I had to simplify a lot of things for him - to explain routines - because his logic was screwed up. He would go from a to c and miss b.
x 53 I was very supportive of him - he was worried about the hole in his head.
x 54 I want to help him if I can rather than leave him.
x 60 I can calm him down.
x 74 I just really tried to stand by him.
x 74 I try not to make him dependent.

x 74 I try to reduce the stress on him.
Xx49 I've done a lot of talking to myself - to cope and not get annoyed with myself.
y 60 I think it helps a lot to be on an acreage.
z 44 I need to wean him from me-he's very demanding.
ZZ76 Trying not to get frustrated-step back from the situation when things occur.

3. Behavior, thought, attitude, outlook b) negative (CC, d, e, EE, II, k, v)

CC71 I just couldn't care anymore.
CC71 I try not to get terribly depresed and not care as much.
d 18 I put up with it.
d 22 I concede a lot of things because I can't follow it up - it upsets my husband too much.
d 54 I back down if there is an argument.
d 54 I watch what I say.
d 62 I don't say anything when he gets angry.
e 23 Sometimes I just tune him out.
e 46 I try to ignore a lot of things going on - put them out of my mind.
e 66 I've insulated myself against him.
e 83 I walk away, ignore his behavior, because reasoning doesn't work.
e 83 I've built a wall and so have the kids - it's like teflon to protect us from his anger.
EE18 I don't want to put negative feelings against my husband with my family so I don't talk about it with them.
EE74 I try to keep problems to myself.
II60 I gave some land back so we could cope with it.
II71 I've given up things.
II77 We were able to give up things to cut back on finances.
k 49 I use medications.
v 23 Sometimes he's like a teenager and I deal with him as I would my teenage sons.
v 35 I had to learn to put my foot down, to be firm with him, sometimes I treat him like a kid, and even yell at him. (At first I had let him make financial decisions and we got further and further into debt.)

5. Faith (S)

S06 Christian faith.
S08 Doing a lot of praying.
S08 My faith keeps me going.
S17 I go to church on a regular basis.
S27 Our church and my faith.
S29 Joined a church organization.
S30 A whole lot of praying.
S30 Church has been a big support. The church has also started a support group for dysfunctional families which I attend.
S32 I prayed.
S33 Church has supported us 100%, helped with the kids, helped spiritually.
S65 I believe in God and I pray.
S68 I did a lot of praying.
S68 I found the Lord.
S68 I get my strength from the Lord.
S83 I do a lot of praying.
S83 I go to church.