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# UNIVERSITY OF SAN DIEGO Philip Y. Hahn School of Nursing DOCTOR OF NURSING SCIENCE

Major Trauma Outcomes: At What Cost? And for Whom?

A Cost-Effectiveness Analysis

by

A. Elaine Bond, APRN, MSN, CCRN

A dissertation proposal presented to the

# FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING

## **UNIVERSITY OF SAN DIEGO**

In partial fulfillment of the

requirements for the degree

DOCTOR OF NURSING SCIENCE

May 1998

**Dissertation Committee** 

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May 1998 A. ELAINE BOND

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#### Abstract

The purpose of this triangulated descriptive study was threefold: (a) to identify the financial costs for acute trauma care, including costs for those who die early in treatment, and who pays those costs; (b) to identify the relationship between costs and severity of injury; and (c) to identify survivor functional and psychosocial costs, or quality of life, not only by current health care outcome criteria, but also from patients' and families' perspectives.

Retrospective review determined the financial differences (total charges of \$9,945,973 and institutional costs of \$7,089,962) for 370 patients' severity of injury and functional outcomes at discharge, using the Glasgow Coma Scale (GCS), the Revised Trauma Score (RTS), the Injury Severity Score (ISS), and the Glasgow Outcome Score (GOS). One-way Analysis of Variance (ANOVA) identified statistically significant differences. Generally, moderately injured patients had higher lengths of stay (LOS) and correspondingly higher financial costs than more severely injured or less severely injured patients. More severely injured patients died in the Emergency Department (ED) or early in acute care; those with minor injuries were discharged sooner, leading to utilization of fewer health care resources by these two groups.

Prospective review examined current physical function among survivors and psychosocial outcomes for survivors and family members. The Functional Independence Measure (FIM) found no significant differences in functional status among patients at 6 months to 1 year, 2 years, 3 to 4 years, or 5 years post-trauma. The Health and Daily Living Form B (HDL-B) survey, completed by 48 patients and 35 family members, identified psychosocial outcomes, with no statistically significant differences among patients or families at 6 months to 1 year, 2 years, 3 to 4 years, or 5 years post-trauma. Compared to community members, patients and families experienced more depression, more visits to mental and non-mental health professionals, fewer activities with friends, less substance (alcohol and tobacco) use, and more activities with families.

Qualitative interviews with 20 patients and 18 family members, using a grounded theory approach, indicated that patients' and families' quality of life has improved post-trauma in spite of minor physical or financial setbacks. They have an increased appreciation for each other, for friends, and for life.

## DEDICATION

This dissertation is dedicated to "my best friend" and husband, Hal Bond. As my soul mate, he has supported me (financially, physically, and psychosocially!) throughout my doctoral studies and has improved the quality of <u>my</u> life. Without his encouragement and gentle prodding, I could not have tackled such a monumental undertaking.

#### ACKNOWLEDGMENTS

Although I am the one who received a DNSc degree, many others made contributions throughout the process. Without their encouragement, support, and assistance, I could not have completed such an enormous task. I am deeply indebted to them and acknowledge their assistance:

BYU College of Nursing for research funds; Research assistants, Michelle Blood and Tiffany Noss, who became so proficient at data collection that they told me, "if you stay out of the way, you won't mess this up;" Dr. Donna Fosbinder, colleague, role model, and mentor, who encouraged me throughout my doctoral education and provided professional insight in qualitative data collection and interpretation; Life Flight personnel for their assistance in locating patients' records, providing computer support, and validating scores for injury severity scoring systems; other professional colleagues, classmates, and family members who listened, counseled, and commiserated through the entire process; neighbor and beloved friend, Bonnie Wells, who cleaned our driveway, mowed our lawn, and helped with "dirt therapy" as needed:

Chair, Dr. Mary Jo Clark for her analytical mind and meticulous attention to detail. She spent untold hours discussing the dissertation process; committee member, Dr. Frank Thomas, medical director of Life Flight, who met with me, nearly weekly, throughout the year and a half of data collection and dissertation writing, providing the context and facilitating my access to the quantitative data; committee members, Dr. Janet Harrison and Dr. Gary Schneider for reading and evaluating the content of my dissertation. My heartfelt "thank you to all of you."

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#### Chapter 1

#### Introduction

In the face of escalating health care costs, and as the United States evaluates access to care for the entire population, the incidence of major trauma continues to increase. Each year, more than 20 million disabling injuries and 93,000 deaths from unintentional injuries result in costs of \$444.1 billion (National Safety Council [NSC], 1997). This does not include intentional traumas—homicides and suicides—that constitute many of the traumatic incidents in the United States. Although the NSC estimated there were 31,000 suicide deaths and 24,000 homicide deaths in 1996, there are no accurate records for these intentional traumas from which to extrapolate costs. Studies that examine financial costs of trauma care do not include major trauma patients who die in the Emergency Department (ED) or during acute care. Although no statistics exist on how many major trauma patients die before reaching the hospital, 8% (Gennarelli, Champion, Copes, & Sacco, 1994) to 27% (Siegel, Shahid, Goodarzi, & Dischinger, 1994) of major trauma patients die in the acute care setting. Mortality and morbidity are higher for those with more severe injuries.

When members of the Emergency Medical System (EMS) respond to a trauma call and assess major trauma patients using trauma scoring systems, a relentless sequence begins to unfold: major trauma patients are assessed, treated, and rapidly moved from the ambulance or helicopter to an ED, to an operating room, to a computerized tomography site; and then into an intensive care unit. Many of these patients are unconscious from their injuries. Other patients are chemically paralyzed and sedated, either to decrease their oxygen consumption or to control their combative behavior (Champion, Copes, Sacco, Lawnick, Keast, et al. 1990). Such patients cannot evaluate their condition or voice their desires regarding care.

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Family members or significant others are also rarely able to state their expectations. Family members may not arrive at the trauma center during early resuscitation, or they may be overlooked as health care providers hurry to perform lifesaving procedures. During initial care, health care providers focus on saving the patient, not on financial costs, long-term outcomes, or quality of life for the patient and/or the family.

After a major trauma, a patient's family members face multiple new circumstances as their lives are changed in seconds. Their work, home, and school schedules are disrupted. Families experience rollercoaster changes of emotions--distress, uncertainty, and hope---with each infinitesimal change in their loved one's status. Initially they may feel relief that the patient is alive; however, overwhelming fear often follows (Kleeman, 1989). They may also have unreasonable expectations that the patient will return to a premorbid level of function.

Health care providers, too, may have unrealistic outlooks and hold out false hopes to families. Trauma center staff may present incomplete information because data on long-term outcomes are lacking, because they think families are unable to make appropriate decisions, or because they wish to spare families unnecessary concern. Although the prognosis is bleak for patients with poor trauma scores (Champion, Copes, Sacco, Lawnick, Keast, et al. 1990; Wisner, 1992), neither patients nor families are usually offered the option of receiving "no care" or minimal supportive care. Trauma centers are teaching facilities dedicated to providing health professional students valuable experience in trauma resuscitation and care. Although these experiences can teach students how to improve care for subsequent patients, such care may conflict with the immediate patient's best interests.

Once the crisis is over, as patients and families try to reorganize their lives, their feelings of relief may change. Patients may have a decreased level of physical function or be neurologically impaired and unaware of their surroundings. Patients may face years of costly rehabilitation to regain former abilities, if ever. Families may face a future with new responsibilities when the patient does not return to former levels of function, but needs extensive care at a rehabilitation center or at an extended care facility. Family or significant-other caregivers (hereafter called families) may have to discontinue normal activities to provide

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around-the-clock home care for a cognitively, physically, and/or psychosocially incompetent patient. Families may face the constant task of being reasonable with an unreasonable head-injured patient. Some must sell personal belongings to meet new treatment-related financial obligations. Many must change or withdraw from employment to care for their trauma patient (Hall et al., 1994). Additionally, if trauma patients have no insurance and families cannot or will not assume financial responsibility, society assumes these burdens (Mackersie, Davis, Hoyt, Holbrook, & Shackford, 1995; Payne, Berne, Kaufman, & Dubrowskij, 1993).

#### Purpose

In light of financial costs, functional and psychosocial outcomes, and the burden placed on families and society, health care providers may need to reexamine care decisions for major trauma patients. Additionally, as people in the United States demand a voice in the health care they receive, ethical considerations require that health care providers address patient and family expectations of trauma care and outcome. This reexamination requires more complete knowledge of the financial, functional, and psychosocial costs of major trauma than is currently available. The purpose of this triangulated descriptive study was threefold: (a) to identify the financial costs for acute trauma care, including costs for those who die early in treatment, and who pays those costs; (b) to identify the relationship between costs and severity of injury; and (c) to identify survivor functional and psychosocial costs, or quality of life, not only by current health care outcome criteria, but also from patients' and families' perspectives.

## Significance to Nursing

Nurses, as patient advocates (American Association of Critical Care Nurses, 1989) and as caregivers at every stage of post-trauma patients' treatment and recovery, must adequately evaluate the outcomes of trauma care. Nurses must have financial cost and outcome cost information with which to educate patients and families about trauma care options, so they can make decisions based on informed perspectives. Nurses also need to incorporate financial cost and outcome cost information into patient conferences as they collaborate with other health care providers to plan appropriate care.

Because nurses are involved at every stage of trauma care--from early rescue teams through ICUs, to rehabilitation and long-term care--they need information to help patients and families through decision-making processes. Those patients who survive the immediate trauma warrant appropriate care. But determining what constitutes appropriate care requires research that identifies patients' functional costs, and patients'/families' psychosocial costs, perspectives, and expectations as well as the financial costs of care. Nurses should be able to use the results of this study to more fully assist major trauma patients and their families to make decisions. Furthermore, the study results may influence changes in current trauma care policy. The author's concern for proper utilization of resources and support of the Patient Self-Determination Act of 1990, which empowers patients to determine what care they will receive, provides the basis for this study.

## Cost Classification Matrix

Although many researchers have examined multiple aspects of costs for major trauma patients, no well-integrated models exist that identify the wide variety of costs in these complex situations. Many previous studies have established financial costs for acute care and for rehabilitation. Some have documented societal financial costs for patients who cannot or will not assume financial responsibilities for care. Some studies have focused on the costs of inappropriate resource utilization when patients who have little hope of recovery deplete blood banks and other supplies.

Many studies have identified outcomes, loosely defined as the ability to return to pre-trauma function. However, when major trauma patients do not return to premorbid function, other costs become evident, such as loss of psychosocial interactions, loss of potential productivity, and loss of physical function. Families experience these costs, too. Additionally, society bears the cost of lost productivity for patients who die or remain unable to function and for family members who leave employment to provide post-trauma care.

Some costs have not been addressed by research at all. There are no reported studies examining financial costs for transportation from the scene or for patients who die in the ED. No comparisons are published for financial costs among patients who die in the ED, those who die while in acute care, and those who survive. No reports detail the financial costs patients and families incur for trips to health care centers, for equipment, retrofitting homes for wheelchairs, or for lost income.

Costs in each of the areas identified above vary, depending on the severity of the original trauma, the amount of care needed, and the length of time until patients return to productivity, if ever. Various studies have identified crucial times at which to assess outcomes; at discharge, at six months postdischarge, one year, two years, and five years.

For this study, the researcher developed a cost classification matrix to identify four types of costs: (a) institutional financial costs for patients; (b) societal financial charges for patients' care; (c) patients' functional, psychosocial, and quality-of-life costs; (d) family psychosocial and quality-of-life costs. Institutional costs and societal financial charges are incurred for patients who die in the ED, for those who die in the acute care setting, and for survivors. Functional, psychosocial, and quality-of-life costs apply only to those patients who survive and their families (see Figure 1).

Patients who are pronounced dead in the ED may have transportation costs only. Financial costs for patients who die in the trauma center, including transportation costs, may range from minor costs to major costs. Those who die during early resuscitation efforts would incur minor costs. Other patients--those who make repeated trips to surgery, require intense resuscitation efforts in intensive care units, or who develop long-term complications, such as infections and multiple organ system failure, incur major costs prior to death. Patients who survive may experience the same gamut of complications and similar financial costs; however, they do not succumb to their injuries, but may experience the costs of decreased function, psychosocial interactions, and quality of life.

Dependent variables in this study will be the institutional financial costs and societal financial charges for care; the physical, psychosocial, and decreased quality-of-life costs for patients, and the

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|   | Financial<br>Charges | Institutional<br>Costs | Physical<br>Function             | Psycho-<br>social<br>Function     | Quality<br>of Life       |
|---|----------------------|------------------------|----------------------------------|-----------------------------------|--------------------------|
| Sources of<br>Payment<br>Commercial<br>Medicare/aid<br>Work Comp *<br>Charity<br>Self-pay<br>Military<br>Crime Victim | S                    | \$                     |                                  |                                   |                          |
| Patients who<br>Died in ED  | S                    | S                      | GCS ک<br>RTS ۶<br>GOS ۴<br>ISS ۶ |                                   |                          |
| Patients who<br>Died during<br>Acute Care   | S                    | \$                     | GCS<br>RTS<br>GOS<br>ISS         |                                   |                          |
| Patients who<br>Survive   | S                    | S                      | GCS<br>RTS<br>GOS<br>ISS<br>FIM  | HDL-B<br>Qualitative<br>Interview | Qualitative<br>Interview |
| Family<br>Members   |                      |                        |                                  | HDL-B<br>Qualitative<br>Interview | Qualitative<br>Interview |

\* Workmen's Compensation <sup>b</sup> Glasgow Coma Scale <sup>c</sup> Revised Trauma Score <sup>d</sup> Glasgow Outcome Score <sup>c</sup> Injury Severity Score <sup>f</sup> Health and Daily Living Form B

Figure 1 Cost Classification Matrix with Measures Used

psychosocial, and decreased quality-of-life costs for the families. Independent variables will be initial trauma scores, and mortality/survival status. The matrix also shows the measures used to assess each type of cost.

Examining patient and family costs for patients who die; for survivors' out-of-pocket health expenses and rehabilitation costs; for providers' fees; and for society's lost productivity is beyond the scope of this study. This cost classification matrix provides an overall cost picture of major trauma patient care that includes financial costs for institutions, financial charges to society, and functional, psychosocial, and quality-of-life costs to patients and their families.

## Research Ouestions

This study addressed the following research questions:

- 1. What are the differences between financial charges and institutional costs for major trauma patients who die in the ED and for those patients who die in the acute care setting?
- 2. What are the differences between financial charges and institutional costs for major trauma patients who die and for those who survive?
- 3. What is the relationship between financial charges and institutional costs and severity of injury as assessed by initial Glasgow Coma Score (GCS)?
- 4. What is the relationship between financial charges and institutional costs and severity of injury as assessed by initial Revised Trauma Score (RTS)?
- 5. What is the relationship between financial charges and institutional costs and severity of injury as assessed by the Injury Severity Score (ISS)?
- 6. Who pays the financial charges of major trauma patients' care?
- 7. What is the relationship between financial charges and institutional costs and discharge outcome for major trauma patients as measured by Glasgow Outcome Score (GOS), for surviving patients?

- 8. What are the differences in physical function costs, as measured by Functional Independence Measure (FIM), for surviving patients at 6 months to one year post-trauma, at two years posttrauma, at 3 to 4 years post-trauma, and at five years post-trauma?
- 9. What are the differences in psychosocial costs, as measured by the Health and Daily Living Form B (HDL-B), for surviving patients at 6 months to one year post-trauma, at two years post-trauma, at 3 to 4 years post-trauma and at five years post-trauma?
- 10. What are the differences in psychosocial costs, as measured by the HDL-B, for families of surviving patients at discharge, at 6 months to one year post-trauma, at two years post-trauma, at 3 to 4 years post-trauma, and at five years post-trauma?
- 11. What is the perceived quality of life for patients and their families post-trauma?

## **Operational Definitions**

#### Major Trauma Patient

For the purposes of this study, a major trauma patient is one who is transported by helicopter directly from the scene of an accident to a Level I Trauma Center as a Level I Trauma patient. Major trauma patients have one or more injuries that are potentially life-threatening or the mechanism of injury places them at high risk for developing serious complications. Examples of specific mechanisms of injury that direct trauma patients to a Level I Trauma Center include (a) a fall of more than 20 feet, (b) ejection of the patient from a vehicle, or (c) death of another person in the accident (Exposito, Offner, Jurkovich, Griffith, & Maier, 1995). Patients under eighteen years of age were excluded because they are transported to a children's trauma center. Burn patients were excluded since they are transported to a nearby burn center. Patients with incomplete acute care data were also excluded.

# Financial Charges and Institutional Costs

Health care institutions, providers, society, patients, and their families bear financial costs. For this study, *financial charges* were the amounts billed to the patient or other payer and *institutional costs*  were the amounts the facility paid to provide care. Since the helicopter service is part of the trauma center, all institutional cost data originated in one center. Financial costs for transportation for these helicoptertransported major trauma patients may differ from those of ground ambulance-transported major trauma patients. This study did not address provider costs (eg. The cost of physician services).

The researcher obtained general subjective nonspecific financial costs for patients and families during structured interviews. Patients and families were asked about the economic impact the injury and subsequent recovery have had for them.

#### Functional Costs

Functional costs are major trauma patients' loss of abilities to provide self-care. This study assumed that these patients provided self-care before the traumatic incident. Patients' scores in the locomotion, mobility, sphincter control, and self-care sections of the Functional Independence Measure (FIM) (Hamilton, Granger, & Sherwin, 1987) were used to determine functional costs. The FIM is discussed more fully in Chapter 3.

# Psychosocial Costs

Psychosocial costs for major trauma patients are expressed as decreased ability to communicate appropriately and/or to engage in normal social interactions. These costs were determined partially by patients' scores in the communication and social cognition sections of the FIM (Hamilton et al., 1987) and by patients' scores on the HDL-B (Moos, Cronkite, Billings, & Finney, 1986). The HDL-B is discussed more fully in Chapter 3. The researcher obtained information on other psychosocial costs through structured interviews with recovering patients capable of communicating.

Psychosocial costs for families are the losses in social functioning and the lifestyle changes families have made to provide care for their major trauma patient. These costs were determined using the HDL-B (Moos, Cronkite, and Finney., 1990) and structured interviews with one family member of the recovering patient.

#### Injury Severity

Injury severity is the extent of injuries sustained in the major trauma event. The Injury Severity Score [ISS) (Baker, O'Neill, Haddon, and Long, 1974), calculated from the list of injuries in the patient's medical record, was used to determine severity of injury,. The ISS is discussed more fully in Chapter 3.

## Discharge Outcome

Discharge outcome is the functional level at which a major trauma patient was discharged from the acute care facility. Outcomes range from death to good recovery. The Glasgow Outcome Scale (GOS), a measure of discharge outcome, (Jennet, Snoek, Bond, & Brooks, 1981) was calculated from the patients' discharge summary in the acute care institution. The GOS is discussed in Chapter 3.

## Quality of Life

Quality of life is the cognitive ability to evaluate one's own life, the perception of a satisfactory state of social, emotional, physical, and mental health, and a feeling of well-being despite physical limitations. Patients and families determined the quality of their lives by their own standards, since quality of life cannot be determined by institutional outcome criteria (Bond, 1996).

## Initial Trauma Scores

The Glasgow Coma Scale (GCS) (Teasdale & Jennet, 1974) and the Revised Trauma Score (RTS) (Champion et al., 1989) were used to indicate major trauma patients' initial physiological responses to injuries. Helicopter nurses or paramedics calculate the GCS and RTS at the scene of an accident. The GCS is specific to head injuries, while the RTS assesses general physiological responses.

## Summary

There is a need for cost and outcome information on which to base trauma care decisions that take into account client, institutional, and societal perspectives. This study is designed to provide information on four types of costs: financial charges to individuals or payers, institutional costs for care provided, physical costs for patients, and psychosocial costs to patients and families.

#### Chapter 2

## Review of the Literature

A review of relevant literature is presented to document the magnitude of concerns surrounding major trauma and its costs, and to identify who pays these expenses. The review includes literature related to the incidence of injury, standards for major trauma care, and previous studies related to financial, functional, and psychosocial costs. Since many authors describe multidimensional aspects of costs for major trauma outcomes, the literature review concludes with an overall discussion of the cited studies.

## Trauma Incidence

Each year in the United States, 57.9 million unintentional injuries occur, with 18.2 million disabling injuries and 90,000 deaths per year. Alarmingly, after previous declines in injury-related deaths, in 1993 injury mortality rates increased for the first time in five years. These statistics cover only *unintentional* injuries. As violence in the United States increases, the number of *intentional* injuries-- assault with weapons---is also increasing rapidly. More than 38,000 deaths a year result from firearm-related events; 47% of which are suicide firearm deaths, 47% homicides, and 4% accidents (NSC, 1997).

## Background

Health care professionals have long recognized that a trauma victim's probability of survival following an accident depends on the severity of the injury, the speed with which treatment is initiated, and the expertise of health care professionals (Trunkey, 1982). Therefore, in 1971, the Emergency Medical Systems Act was written, with revisions in 1973 and 1976, to provide specific care guidelines for Emergency Medical Technicians (EMTs) and Paramedics. This legislation helped to reduce morbidity and mortality by identifying and standardizing required prehospital care (Boyd, 1982, 1983: Boyd & Cowley,

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1983). Thereafter, rapid stabilization and transfer of trauma victims significantly decreased the time before specialized interventions could be initiated (Trunkey, 1982).

To provide appropriate hospital care for trauma patients, the American College of Surgeons Committee on Trauma (1979, 1983, 1993) established guidelines for Level I, II, and III trauma centers. Currently, victims of major trauma are transported to Level I facilities, which must have emergency room physicians proficient in critical care delivery, general and neurological surgical services, computerized tomography, intensive care units (ICUs) with a maximum nurse:patient ratio of 1:2 each shift, and a trauma research/teaching program in place.

To facilitate rapid assessment of injury severity and to assure treatment commensurate with injuries, trauma scoring systems were developed to measure physiological data. These systems are used for prehospital triage and to determine the type of hospital facility most appropriate for a particular trauma patient. The principal trauma scoring systems are the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974), the Trauma Score (TS) (Champion, Sacco, Carnazzo, Copes, & Fouty, 1981); the Circulation, Respiration, Motor, and Sensory Score (CRAMS) (Gormican, 1982); and the Revised Trauma Score [RTS) (Champion, Sacco, Copes et al., 1989).

The GCS, a physiological scoring system, assesses impaired consciousness and coma. It provides a patient's best response in three functions: eye opening, verbal response, and motor response. Because many major trauma patients have a neurological component to their injuries, elements of the GCS were incorporated into the other trauma scoring systems.

The CRAMS score combines physiological and clinical criteria for assessing injury severity. It assesses the presence and quality of vital signs, abdominal or chest pain, motor abilities, and the quality of speech (Gormican, 1982). The TS assesses physiological and clinical findings of respiratory rate, respiratory effort, systolic blood pressure, capillary refill, and includes a coded value for the GCS (Champion et al., 1981). The RTS was created to simplify the TS for more effective triage. It eliminates respiratory effort and capillary refill as assessment criteria. It assesses the other parameters of the TS and reassigns the points accrued (Champion, et al., 1989). (See Chapter 3 for a complete discussion of the GCS and RTS.)

As hospital administrators and health economists began to recognize the enormous outlay of financial resources required for trauma care, they required cost/benefit and quality assurance analyses (Ehrat, 1987). The American College of Surgeons Committee on Trauma (1986) developed audit filters for institutions to evaluate the effectiveness of care. As a further impetus for trauma care evaluation, the Joint Commission on Accreditation of Health Care Organizations (JCAHCO) (1989, 1994) also requires quality assurance analyses for trauma care.

Over the years, trauma organizations and researchers have developed a variety of ways to measure trauma outcomes. The Abbreviated Injury Scale (AIS) (Committee on Injury Scaling, 1985) and the Injury Severity Score (ISS) (Baker et al., 1974; Baker & O'Neill, 1976), were developed as research instruments to quantify the extent of injuries sustained by major trauma patients. The AIS proved to have a major limitation in that it did not provide a way to incorporate multiple injuries. Building upon the AIS, the ISS provides information about multiple injuries sustained by summing the scores for injuries to different parts of the body. The ISS cannot be performed at the scene of an accident but can be calculated within 24 hours of hospitalization when all injuries are identified.

Other instruments were developed for research, such as the Trauma Score and Injury Severity Score (TRISS) (Boyd, Tolson, & Copes, 1987) and A Severity Characterization of Trauma (ASCOT) (Champion, Copes, Sacco, Lawnick, Bain et al., 1990). TRISS and ASCOT focus on morbidity versus mortality, with little definition of levels of morbidity. The Glasgow Outcome Scale (GOS) (Jennet et al., 1981) further divided survivors of traumatic brain injury into categories that ranged from a persistent vegetative state to normal function. (Further discussion of the GOS is presented in Chapter 3.) Although the AIS and ISS measure severity of trauma patients' injuries and the GOS evaluates their neurological disability at discharge, none of these tools evaluates or predicts functional outcome. The Functional Independence Measure (FIM) (Hamilton, Granger, & Sherwin, 1987) alleviates that deficiency by evaluating patients' abilities in self-care, sphincter control, mobility, locomotion, communication, and social cognition. (Detailed discussion of the FIM appears in Chapter 3.)

Each trauma center and most states have developed trauma registries that organized trauma data for analysis using a variety of the available scoring systems and methods. However, comparisons between facilities have been difficult because the validity and reliability of data were inconsistent (Brotman et al., 1991; Paine & Waller, 1989; Pollock & McClain, 1989). Consequently, through the American College of Surgeons' Committee on Trauma, one hundred thirty-nine trauma centers voluntarily submitted data for 80,544 trauma patients to a national data base (Champion, Copes, Sacco, Lawnick, Keast, et al., 1990). The statistical probabilities from that data base, the Major Trauma Outcome Study [MTOS), provide the standard criteria by which trauma centers now measure outcomes [survivor probabilities].

#### **Financial Costs**

The NSC (1997) estimated that the annual cost of accidental injuries is \$444.1 billion per year. Of that figure, the NSC places medical expenses at \$74.6 billion, with wage and productivity losses at \$224.7 billion. Other costs include administrative expenses, fire loss, motor vehicle damage, and employer costs. Each of these other costs warrants further inquiry, but they are not within the scope of this study. The NSC further estimated that lost quality of life costs an additional \$1,027.9 billion, for a total accidental trauma cost of \$1,472 billion per year (p. 4). Intentional traumas--homicides and suicides--- constitute many of the traumas in the United States, but those patients were excluded from the NSC estimates, since no accurate records exist from which to extrapolate costs.

Many studies show that elderly trauma patients utilize a disproportionate amount of available resources. McMahon, Schwab, and Kauder (1996) reported elderly patients have more pre-existing physiological health concerns that leave them with fewer reserves with which to overcome major trauma. This leads to more complications, more days of hospitalization, and, consequently, higher utilization of health care resources. MacKenzie, Morris, Smith, and Fahey (1990) reported that trauma patients aged sixty-five and older (12% of all trauma patients), accounted for 25% of the trauma charges. Elsewhere

(Bennett, Jacobs, & Schwartz, 1989) 79% of patients over sixty years of age with GCS scores below six died in the hospital, compared to 36% of such patients 20 to 40 years of age. Using the GOS to measure outcomes, 2% of Bennet et al.'s elderly patients "recovered favorably" (one patient!), at an overall charge of \$1.5 million in charges, compared to favorable recovery for 38% of the younger patients, whose total charges were \$2.9 million, or \$154,000 each (p. 791).

Emhoff, McCarthy, Cushman, Garb, and Valenziano (1991) found 62% of the 109 trauma patients they evaluated went to rehabilitation centers and 38% were discharged directly home. For the patients who went to rehabilitation, acute hospitalization periods were longest for persons with head and musculoskeletal injuries (average of sixty-six days), next longest for individuals with isolated head injuries (average thirty-eight days), and shortest for those with musculoskeletal injuries only (thirty-six days). Patients who were discharged home had twenty-eight day average lengths of stay. Although Emhoff et al. did not examine the financial costs for these patients, one would expect that those who spent more days utilized larger amounts of materials and human resources.

Schwab, et al. (1988) found that the highest costs for trauma patients corresponded with the worst ISS scores, but, surprisingly, reimbursement did not. For those with ISSs of more than 40, average per patient costs were \$19,845, yet reimbursement was \$8,187. Bennett et al. (1989) calculated that 49% of \$6.9 million their center recorded in trauma care costs was nonreimbursable. Furthermore, 11% of patients died at that trauma facility during hospitalization, despite major expenditures.

In a study of 429 air-evacuated trauma patients, Bond, Thomas, Menlove, MacFarlane and Petersen (1992, 1993) found that acute care costs totaled \$7.8 million. Seventy-five patients with the three lowest GCS scores (3 to 5) cost \$1.95 million, or an average of \$26,000 each. Fifty-nine percent of these patients with low GCS scores died before leaving the acute care setting; 33% were discharged to extended care facilities; 5% went to rehabilitation centers; and .025% went home, but still needed supportive care from family members. Using CRAMS scores to assess injury severity, 107 of the same patients fell into the five lowest categories (no patient had a zero) and cost \$2 million, or an average of \$18,691. Fifty-one percent died, 40% went to an extended care facility, 15% went to rehabilitation facilities, 4% needed

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supportive care at home, and one patient left the hospital with no recognized need for additional care. Of the 51% who died (261 patients), .03% had the better GCS scores of 13, 14, and 15. Total costs for the patients with better GCSs were \$3.6 million, or \$13,720 each. There were also .03% of 252 patients with CRAMS scores of 8, 9, and 10 who died. The 252 patients cost \$2.99 million, with average costs of \$11,898.

Substantial financial costs are sobering, but how those costs are distributed is also alarming. As early as 1988, trauma centers experienced reimbursement problems, based on diagnosis-related-groups (DRGs) (Schwab et al., 1988). In a one-year study to determine costs, Schwab et al. found that patients outside the normal length of stay for a certain DRG--those with worse injuries--cost an average of \$15,694, but the trauma center received only \$8,495 per occurrence. Based on these figures, Schwab et al.'s trauma center could lose \$1.86 million in one year.

DRG reimbursement continues to plague trauma centers (Siegel et al., 1994). In Siegel et al.,'s data, mean acute care costs for motor vehicle accidents were \$74,310 (including professional fees). They stated that variation for major trauma patients--\$3200 to more than \$300,000--is log-normal. DRG assumptions are based on Gaussian simple-normal, and payment does not include accurate costs. Siegel et al. stated the highest costs for trauma patients corresponded with the worst trauma scores, but reimbursement did not.

Additionally, the burden of cost for major trauma care often falls on the public, especially when related to high-risk behaviors. Two recent studies (Mackersie et al., 1995: Payne et al., 1993) showed high percentages of major trauma patients' care paid for by taxpayers. In Mackersie et al.'s examination of high-risk behaviors--not wearing motorcycle helmets or seat belts, combining alcohol or drug use with driving, and intentional trauma--they found significant differences in those for whom public funding paid financial costs. Payne et al pointed out that there were more admissions at their facility for gunshot wounds than for "acute appendicitis (681) and gallstone-related conditions (601)" (p. 279.) They reported that public funding provided 87% of the \$5.4 million (\$7,932 per occurrence) for gunshot patients at their trauma

center. These statistics clearly indicate a significant proportion of societal resources going to trauma patients.

In what they called the "cost of futility" (p. 468), Rosemurgey, Norris, Olson, Hurst and Albrink (1993) found that when major trauma patients required Cardio Pulmonary Resuscitation (CPR) at the scene, *none* of the patients lived. Although some may argue that such trauma patients provide organs for transplantation, only 8% of these patients donated anything, and what they did donate were corneas. Recovery of corneas does not require transport before declared death. The cost for acute care for these 138 patients was \$703,180, after ground transport costs of \$46,100 and air transport costs of \$63,952, for a total of \$871,186.

Similarly, Pasquale, Rhodes, Cipolle, Hanley, and Wasser (1996) found that 106 major trauma patients required CPR at the scene. One hundred three of the patients died, with in-hospital costs greater that \$4,000 per patient. Three of their patients survived, at a mean cost of \$34,027.

The financial studies discussed here validate the NSC's figures; financial costs for trauma care are indeed high. These studies also address concerns that (1) for major trauma patients, trauma centers may be inadequately reimbursed when payment is based on DRGs or a similar schedule of payment; (2) care for many of these patients may be futile, since many will die regardless of care; (3) this may be inappropriate utilization of health care resources; and (4) society, or public funding pays a large proportion of the financial costs for trauma care.

Besides the financial costs already cited for the acute hospital care of major trauma patients, by the end of the first post-trauma year, 47% of the family caregivers in one survey had changed or relinquished their employment to care for the patient (Hall et al., 1994). Two years after the trauma event, that figure dropped to 33%, but 22% of the families indicated they did not have sufficient funds for expenses. Such financial costs to families add to the psychosocial concerns experienced by patients and families.

#### Functional Costs

Although the AIS and ISS measure severity of trauma patients' injuries and the GOS evaluates their neurological disability at discharge, none of these tools predicts long-term functional outcome. That is, they measure anatomical injuries and neurological responses, rather than physical function. If patients' initial injuries are corrected, theoretically the patients could function normally. However, such an expectation is unrealistic. Many injuries are irreparable and preclude return to function. Brenneman, Boulanger, McLellan, Culhane, and Redelmeier (1995) found that 54% of the major trauma patients from their study who had ISS scores greater than 50 died during hospitalization, and had much shorter lengths of stay (16 days versus 92 days for survivors). Even after 27 months, the survivors continued to have physical disabilities. Similarly, Quigley et al. (1997) reported 93% of the major trauma patients in their study (308 out of 330 patients in a five year period of time) with initial GCS scores of 3-5 died.

Using the FIM, Emhoff et al. (1991) evaluated 109 patients to track disability and return to function. The patients who were discharged to go home had 50% of their normal function, but those who went to rehabilitation centers had only 25% of their normal function. The evaluators also found that 91% of head-injured patients, although they were physiologically functional, went to rehabilitation centers. Of those with musculoskeletal injuries, 43% went to rehabilitation centers. Sixty-six percent of the patients who had both head and musculoskeletal injuries went to rehabilitation. Those patients who were sent home regained function at a much faster rate than did those who went to rehabilitation. This reaffirms what common sense would indicate--that patients with less severe injuries may return to function faster and therefore utilize fewer health care resources.

Health care providers and trauma survivors may differ in their perceptions regarding the outcomes of care. A landmark follow-up study presented at the annual American Association for the Surgery of Trauma Conference ignited interest in "late" outcomes (Frutiger et al., 1991). Frutiger et al. reported that patients' perceptions of their quality of life differed greatly from physicians' evaluations. Using the GOS, physicians indicated 89% of the study population was "healthy or slightly disabled," 9% were severely disabled, and 2% were in a persistent vegetative state. These patients saw themselves differently: 45% reported moderate physical disability and 30% reported psychological or cognitive disability. One-third described overall "disturbed social relations" (p. 1223). Only 26% of the patients said their quality of life was good, and 74% percent reported a decreased quality of life. At the end of two years, <u>no</u> patients were working. At five years, 79% had returned to work, but 35% of them related significant interpersonal difficulties in the workplace. Clearly, patients' expectations of post-trauma outcome, as well as statistics regarding probabilities of outcomes, should be factors in deciding treatment for such patients.

#### Psychosocial Costs

A study released simultaneously with Frutiger et al.'s (1991) determined that survival did not equate to quality of life (Landsman et al., 1990). One hundred thirty-seven patients from one trauma center, whose data were entered into the MTOS, were recruited to complete self-reported questionnaires on the psychosocial consequences of major trauma. The study showed that psychiatric symptoms produced financial and employment problems, so that one-third of the subjects had injury-related difficulties with employment. Landsman et al. stated that *subjective* or patient's perspectives were better predictors of psychosocial outcome than the severity of injury.

An earlier study showed similar results. Gensemer, McMurry, Walker, Monasky, and Brotman, (1988) used the Halstad Impairment Index (HII) with sixty-five post-trauma patients who were referred because of "cognitive difficulty and personality changes" (p. 44). The results showed that 65% of the patients had returned to work, but 35% had not. Those who returned to work had higher HII scores and better ISS and GCS scores. Stratton and Gregory (1995) similarly found that traumatic brain injury can lead to personality changes, leading to psychosocial problems for families and friends of the patient. In a prospective observational study with subjects similar to Stratton and Gregory's, Thiagarajan, Taylor, Hogbin, & Ridley (1994) used the Perceived Quality of Life Score and Nottingham Health Profile to determine that 62% of their subjects experienced "severe social disability and moderate-to-severe (work) impairments" (p. 212). For these patients, scores indicated significant differences in quality of life with respect to happiness, leisure activities, overall health, capability to think appropriately, employment, and income.

In contrast, Dikmen, Ross, Machamer, and Temkin (1995) reported that objective indices of psychosocial outcomes, such as employment, correlated better with the severity of head injuries than limitations identified by patients through the Sickness Impact Profile (SIP). Dikmen et al. evaluated head injured patients, non-head injured patients, and community controls. They stated the head injured patients had continued psychosocial limitations at one year post trauma.

In a prospective longitudinal quality of life study for patients with anxiety disorders, using the Survey-Community Interview-Wave and Schedule for Affective Disorders and Schizophrenia--Lifetime Version, Warshaw et al. (1993) discovered that more than one-fourth of the subjects were trauma survivors. These individuals had significantly higher rates of unemployment, poorer role function, more suicide attempts, increased alcohol abuse or dependence, reduced health status, less stable emotional status, and more dissociative experiences than those who had experienced no trauma.

In interviews to examine patient and family perspectives following traumatic brain injury, Condeluci, Ferris, and Bogdan (1992) found that patients and families placed more emphasis on employment with income and the ability to live independently than on functional skills. Condeluci, et al. also found that although patients valued skills, they valued relationships more. In a similar vein, Stambrook, Moore, Peters, and Zubeck (1991) interviewed 72 neurologically injured patients and found that their difficulties, such as agitation, irritability, and rigidity in cognitive functions, decreased their ability to interact with others. Such disruptions interfered with the families' long-term psychosocial adaptation. Additionally, it was difficult to separate functional outcomes and the related psychosocial consequences.

In a Medline search covering the years 1985 to 1995, Schnyder and Buddeberg (1996) found limited discussion of psychosocial effects surrounding trauma. They recommended more studies to examine psychosocial outcomes as well as functional outcomes to enhance healing for patients and families.

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#### Interrelated Psychosocial and Functional Costs

Several studies indicated there is a relationship between functional and psychosocial costs. A nursing study to investigate both functional and psychosocial sequelae of severe physical trauma (Strohmyer, Noroian, Patterson, & Carlin, 1993) found that seventeen of the eighteen patients studied had complete restoration of physiological function, but all of them had difficulties with psychosocial adaptation. The patients had "severe" problems with hostility, anxiety, guilt, and depression. Furthermore, psychological dysfunction and psychosocial support both influenced these patients' ability to resume work. Other researchers (Glancy et al., 1992) identified several factors that negatively influenced the return to pre-trauma function by trauma survivors, including decreased income because of physiological disability and diminished psychosocial interactions, particularly among patients with lower levels of education. Gensemer et al. (1988) reported that neuropsychological problems, such as poor memory, disinhibition, and frustration intolerance, interfered with ensuing employment status of post-trauma patients. McMahon et al. (1996) also reported that functional changes influenced psychosocial changes, both of which affect patients, their families, and society.

In a study to examine psychological well-being, quality of life, and degree of disability for trauma patients. Holbrook, Hoyt, Anderson, Hollingsworth-Fridlund, and Shackford (1994) found patients' functional limitations and depression were significantly associated (p < 0.05). Eighty-one percent of their population was depressed at hospital discharge and 43% at three-month follow-up interviews. Holbrook et al. discovered social support decreased between discharge and follow-up interviews, but that social support did not affect functional outcome. Their operational definitions included a GCS greater than 12, which eliminated those with serious head injuries.

Looking at the MTOS patients, Gennarelli et al. (1994) determined that head injuries were responsible for 60% of the deaths, but only one third of the trauma events. Gennarelli et al. then used the FIM to find that survivors with isolated head injuries have better physiological function but worse psychosocial function caused by some of the behavioral problems discussed above. Similarly, Dombovy and Olek (1997) reported patients had minimal physiological disabilities by three months, but 50% were

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experiencing decreased psychosocial interactions at three months. By six months, only 33% were still experiencing poor psychosocial outcomes.

After examining outcome for severe traumatic brain injury patients, Boake and High (1996) argued that outcome measurement tools that address only physical function overlooked the interpersonal interactions of psychosocial aspects, which are important indicators of overall outcome. Clearly, when one examines traumatic injury and outcome, damage to the head carries greater risk of poor life adjustment than injury at other sites.

People who knowingly participate in risk-taking behaviors increase their odds of being injured in accidents (Frutiger et al., 1991, Mackersie et al., 1995). Such behaviors, which sometimes preclude an adequate education or employment before injury, may also interfere with a good psychosocial outcome after a major trauma event. Hall et al. (1994) found that 27% of major trauma patients and 22% of the family caregivers in their study had "at risk psychosocial histories" before the trauma episode. Risk factors included alcohol dependence, drug dependence, mental health counseling, psychotropic medications school difficulties, suicide attempts, arrests for other than traffic violations, and incarceration. Two years after the trauma, percentages had increased to 49% and 35%, respectively. Although family caregivers, post-trauma, showed no increased risks for suicide attempts, arrests for other than traffic violations, or incarceration, patients increased in each of those areas.

Others also found high alcohol use and risk-taking behaviors among trauma patients: Peek-Asa and Kraus (1996) reported 42% of the motorcycle drivers in their study tested positive for alcohol, and Hawkins, Lewis, and Medeiros (1996) reported 58% of their subjects had elevated blood alcohol levels. Clearly, the psychosocial precursors and the aftermath for trauma patients and their families may be as disconcerting and detrimental as the original injuries.

In summary, common causal factors can increase both functional and psychosocial costs: loss of physiological function can have a negative influence on psychosocial function. Conversely, limited psychosocial function, both pre-trauma and post-trauma can decrease physiological functioning. In many of the studies cited here, it is difficult to separate the two costs from each other.

#### Discussion

Sadly, trauma is a preventable event that represents some social ills of our day. Safety issues, such as failure to use seat belts and helmets, the acquisition of guns, and the intake of alcohol before driving clearly increase the incidence of traumatic events (NSC, 1997, Mackersie et al. 1995). *Unintentional* injuries are the leading cause of death and disability among all persons aged one to thirty-eight in the United States. They are the fifth leading cause of death for all ages (NSC, 1997).

Alarmingly, the latest national statistics show deaths and disabling injuries have been increasing since 1993, with 93,400 people dying and 20.1 million sustaining disabling injuries in 1996. To put those figures in perspective, every two seconds someone suffers a disabling injury and every five minutes someone dies of a traumatic event. Financial costs for these injuries equals 58% on the national expenditure for food (NSC, 1997) Patient outcomes after major trauma care, with its tremendous physical and psychological costs, and staggering financial costs need to be reevaluated.

The overall outcome of major trauma has been examined from many perspectives by numerous researchers. Three predominant themes have emerged: probability of survival; the degree of function at discharge; and, less predominantly, the psychosocial repercussions for patients and their families following major trauma. Cost-benefit analysis studies have addressed the costs of care from an institutional standpoint--did patient survival equate with expenditures? Other cost studies focused on difficulties with reimbursement. Relatively few examined decreased employment and its attendant reduction in income for patients and families. No studies address the financial costs to society, particularly, nor has anyone addressed the economic or psychosocial costs for patients who remain in extended care facilities. Only one published reported study that identified costs for major trauma patients who died during transport or early in acute care (Rosemurgy et al., 1993).

Few studies of trauma's aftermath identify psychosocial problems (Landsman et al., 1990; Stambrook et al., 1991; Thiagarajan et al., 1994; Warshaw et al., 1993). Fewer still have evaluated patients' or families' perceptions of satisfactory outcomes (Condeluci et al., 1992). In fact, Dittuno (1992) cautioned against using quality of life and life satisfaction scales---"subjective or quasiobjective measures"

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(p. S303)--to evaluate outcomes. He clearly objected to individual perspective, preferring to base judgments about post-trauma outcomes on functional loss. This is consistent with Donabedian's (1992) definition of outcomes, "... states or conditions of individuals and populations attributed or attributable to antecedent health care" (p. 356). Dittuno's and Donabedian's positions are compatible with cost-benefit analysis from an institutional point of view, reflecting a program's economic efficiency (Rossi & Freeman, 1993).

Although some studies in the literature directly address quality of life from a patient or family perspective (Glancy et al., 1992; Holbrook et al., 1994; Landsman et al., 1990; and Thiagarajan et al., 1994), most do not. Other authors include the words "quality of life" in their outcome discussions, but, as evident from their texts, the authors were addressing function, cost/benefit analysis, morbidity and mortality, and age-related complications (Boyd et al., 1987; Dittuno, 1992; Emhoff et al., 1991; Gensemer et al., 1988; Gerhart, 1991; Morris, Sanchez, Bass, & MacKenzie, 1991).

Most studies that discussed economic "costs" did not differentiate between *costs*--what it actually cost the facility to provide care--and *charges*--the bill presented for care (Bennett et al., 1989; MacKenzie et al., 1990; Schwab et al., 1988). In some cases, the two terms were used interchangeably; in others, costs were estimated. Bond et al.'s costs (1993) were actual measured costs. Despite the method used, since the dollar difference between costs and charges may be substantial and varies among institutions based on their costing practices, one cannot broadly generalize financial costs across the spectrum of trauma care. Standardizing the costs with Z scores would enable institutions to more clearly compare studies.

Only one of the studies cited here included professional fees in their cost discussions. Nevertheless, all the financial studies cited clearly show enormous financial outlays for trauma care. Also evident is the lack of any clear relationship between outcomes--function and psychosocial--and costs. The categories merge and each contains aspects of the others.

Rarely are patient and family autonomy discussed, or the choices they might have been offered at the initiation of trauma care. For example, Dittuno's (1992) position that objective measures of satisfactory post-trauma outcomes are the only useful indicators ignores the current move in the United States toward patient autonomy and patient's rights. The subject of high financial costs for patients with low scores on trauma indicator scales is neglected in related studies, although all imply that such patients die in the first twenty-four hours, or soon afterward, from the complications of their injuries. There is no discussion in the literature to suggest collaboration among health care professionals from diverse disciplines and/or patients/families to determine a long-range plan of care for major trauma patients.

Even the data we do have are seriously limited because of the nature of patients who are included or excluded. Patients who die enroute to the hospital, those who die in the Emergency Department, and those who die during acute hospitalization are excluded (Champion, Copes, Sacco, Lawnick, Keast, et al., 1990; Cogbill, Steenlage, Landercasper, & Strutt, 1991). Most patients who die soon after admission to acute care facilities or who remain dysfunctional cognitively and/or psychosocially are those with head injuries. They cannot adequately answer questions or perform functional tests; therefore, they are repeatedly excluded from the studies (Landsman et al., 1990, Holbrook et al., 1994). Instead, follow-up studies are slanted toward patients with less severe injuries and with intact abilities to communicate. The seriously wounded patients and their families are, in effect, eliminated from consideration.

The MTOS baseline survey (Champion, Copes, Sacco, Lawnick, & Keast, et al., 1990), which is currently the standard criterion against which trauma centers measure their outcomes, eliminates all patients who require chemical paralysis and sedation during initial resuscitation. Except for the MTOS, most of the studies cited here include small numbers of participants and exclude many trauma patients who did not qualify because their severe head injuries rendered them unable to participate, cr who later withdrew from the studies (Holbrook et al., 1994; Strohmyer et al., 1993). For the patients Landsman et al. (1990) analyzed, looking at psychosocial consequences of trauma, only 10% of those who were eligible participated in the study. Additionally, gender, ethnicity, alcohol levels, and type of injury differ for the responders versus the nonresponders.

Some studies required the participants to speak English (Landsman et al., 1990; Strohmyer et al., 1993). Nearly one-third of these participants were lost during follow-up (Holbrook et al., 1994; Landsman et al., 1990; Strohmyer et al., 1993; Thiagarajan et al., 1994). Additionally, those who died after discharge

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initially had lower trauma scores than did the survivors. Such an aftermath slanted the final data even more toward survivors whose injuries were less severe. Another study required patients to have a local telephone and address (Holbrook et al., 1994). This requirement that would eliminate many patients, since most trauma centers serve diverse populations from widespread areas. Obviously, the limitations of these studies and the inability of many patients to respond seriously hamper the realistic ability to truly appreciate the complexity and seriousness of the outcomes, costs, and quality of life issues presented by trauma patients.

Many scholars who analyzed the outcome of trauma therapy have implicitly or explicitly defined outcome as morbidity/mortality statistics, return to functional life, or economic cost (Bennett et al., 1989; Bond et al., 1992; Boyd et al., 1987; Champion, Copes, Sacco, Lawnick. & Keast, et al., 1990; Dittuno, 1992; MacKenzie et al., 1990; Sacco et al., 1994). Such cost-benefit analyses of major trauma are unrelated to long-term outcome, but pertain only to physical function at discharge. Although these functional outcome studies are admirable for their quality assurance data, since most indicate survival probability and physical function, they do not incorporate patient and family perspectives. That the patient is alive may be a reassuring outcome to health care providers, but may be less acceptable to the patient and family. If one is to determine the psychosocial health costs to these patients or families, functional outcome, and economic criteria are inadequate. One must clearly identify for whom there are costs--financially, psychologically, socially, and physically--and for whom there are benefits. If the majority of the costs are to patients, families, and society, and the benefits are to health care providers and institutions, ethical concerns require reconsideration of present trauma care policies.

In addition to the limitations listed above, the sudden and unpredictable nature of trauma episodes makes it difficult to generalize findings. A full spectrum of age, physiological injuries, and attendant psychosocial repercussions is involved. Many trauma patients die of complications, rather than from their initial injuries. People who knowingly participate in risk-taking behaviors increase their odds of related injuries and may have lifestyles that interfere with a good psychosocial outcome after an accident. Additionally, many major trauma patients, and particularly those who engage in risk-taking behaviors, have no means to pay for their care.

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Clearly, past research is helpful in identifying major problems in our understanding of trauma outcomes. However, the limitations of the cited studies indicate many areas that require additional analysis to facilitate changes needed by trauma patients and their families. The study reported here was designed to examine the expenditures for patients who die in the ED, or an acute care center, and for those who survive to be discharged. It examined who pays these expenses and explored functional and psychosocial costs for patients and their families, along with longitudinal changes in patients' outcomes. The results provide an overall cost-effectiveness analysis of major trauma patient outcomes from multiple perspectives.

#### Chapter 3

## Methodology

This triangulated descriptive study, with both quantitative and qualitative methodologies, was designed to determine the cost-effectiveness of major trauma care. Retrospective review was used to identify acute care financial charges and institutional costs for all helicopter-transported major trauma patients who died in the emergency department (ED) of the trauma center, during acute care, or who survived to be discharged. It also identified differences in financial charges and institutional costs based on severity of injury. Cohort analysis was undertaken to identify functional costs for patients, psychosocial costs for both patients and families, and quality-of-life data as experienced by patients and families— six months to 1 year, 2 years, 3 to 4 years, or five years post-trauma.

## **Participants**

Participant selection took place in three of the study's four phases. First, all the major trauma patients in LDS Hospital's trauma registry who were helicopter-transported directly from the scene of an accident were included in the institutional costs portion of this study, after approval from the University of San Diego's Committee on the Protection of Human Subjects and LDS Hospital's Research and Human Rights Committee (See Appendices A and B). Subsequently, the researcher attempted to contact all the survivors by telephone to inform them of the purpose of the study and to solicit volunteers for later phases. After signing consent forms (See Appendices C and D for the consent forms), all volunteer dyads--the surviving major trauma patient and a significant other--received HDL-B questionnaires to complete and return to the researcher, via a postage-paid envelope. Finally, a stratified random sample of participants who completed the HDL-B were invited to receive the functional assessment and be interviewed.

For the interview, participants were to be selected in strata of five post-trauma periods--six months, one year, two years, three years, and five years post trauma. The investigator planned to take a proportional random sample from each stratum (Hinkle, Wiersma, & Jurs, 1994 p. 160). For instance, if 20% of all the patients were in the six months post-trauma group, then 20% of the interview sample were to be drawn from the immediate post-trauma group and a proportional sample was to be drawn from the other groups. Participants included the trauma patient and a person regarded by the trauma patient as the most significant other. All major trauma patient survivors and their significant others had the potential to participate in the HDL-B questionnaire portion of the study. The number of participants for the stratified random sample (to whom the FIM was administered and with whom qualitative interviews occurred) was to depend on the number of major trauma patient survivors and their significant others that agreed to fill out the HDL-B.

There were to be a minimum number of five participant dyads in each cohort. However, there were only five major trauma patients from 1996 (6 months to 1 year post-trauma) and four from 1992 (4 years post-trauma) who returned the HDL-B. The researcher drew numbers from a hat for 1991, 1993, and 1994 to determine which major trauma patients and families to interview. She attempted to reach all of the patients who had completed the HDL-B in the 1992 and 1996 post-trauma groups.

## Instruments

#### Glasgow Coma Scale (GCS)

In 1974, Teasdale and Jennett produced a physiological scoring system, the GCS, to assess impaired consciousness and coma. Previous systems lacked specificity, describing only general characteristics of patients with decreased neurological status. Health care providers had no objective method to delineate patients' levels of consciousness. Misunderstandings occurred when patients were referred to other facilities or when patients from different institutions were compared.

The GCS is based on a patient's best response in three functions: eye opening, verbal response, and motor response. The best score, 15, would mean the patient opens his or her eyes spontaneously. speaks appropriately, and can move on command. The worst score, 3, would mean the patient does not open his/ her eyes, does not speak, and does not respond in any way to painful stimuli (see Appendix E for visualization of the GCS and how to score each section). When the GCS was initially tested in the cities of New York, Newcastle-upon-Tyne, and Rotterdam, interrater reliability was greater than 95% (Teasdale & Jennett, 1974). Because the GCS can be assessed easily with little expertise and has a high interrater reliability, both in the field and in the hospital, most other trauma scoring systems have incorporated it. Flight nurses and paramedics calculate the GCS at the scene of an accident and write it in the patient's Emergency Medical Services report.

## Revised Trauma Score (RTS)

Champion et al. (1981) developed the Trauma Score (TS), later endorsed by the American Trauma Society. The TS assessed the physiological and clinical findings of respiratory rate, respiratory effort, systolic blood pressure, capillary refill, and a coded value for the GCS. However, capillary refill and respiratory effort were difficult to assess under adverse conditions. Therefore, to simplify the TS for more effective triage, Champion et al. (1989) revised the TS and produced the Revised Trauma Score (RTS). The RTS eliminated capillary refill and respiratory effort as indicators of injury severity.

The RTS provides coded weights for GCS, systolic blood pressure, and respiratory rate. The best score--12--would mean the patient had a GCS of 13 to 15, a systolic blood pressure greater than 89, and a respiratory rate of 10 to 29 breaths per minute. The worst score--0--would meant the patient had a GCS of 3, no measurable systolic blood pressure, and no respiratory rate. (See Appendix F for visualization of the RTS and how to score each section.)

The RTS was developed from a data base with 2,166 patients. It was tested for validity with data for 26,000 trauma patients from trauma centers in the United States and Canada.

The RTS has become the standard physiological score for trauma assessment throughout the United States. Flight nurses and paramedics calculate the RTS at the scene of an accident and write it in the patient's EMS report. However, the Utah State EMS system used the CRAMS scale before 1996 and

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adopted the RTS during calendar year 1996: therefore, there is no uniform physiological assessment system recorded in each patient's data. For this reason, the researcher computed the RTS for all major trauma patients who were transported via helicopter, directly from the scene of an accident, using the GCS, the blood pressure, and the respiratory rate, all of which are documented in the patient's EMS report.

#### Injury Severity Score (ISS)

In 1974, Baker et al. extended the Abbreviated Injury Score (AIS) previously developed by the American Medical Association (1971) into an anatomical scoring system, the Injury Severity Score (ISS). The AIS (Committee on Injury Scaling, 1980, 1985 updates) ranked individual injuries from 1 to 6, with a score of 1 representing a minor injury and a score of 6 representing a lethal injury. The AIS did not provide a way to incorporate multiple injuries into the data base. If more than one injury was sustained, the AIS did not allow a combination score; the ISS overcame that inadequacy. The ISS provides information about multiple injuries sustained by a trauma patient by summing the squared scores for the three most serious injuries to differing parts of the body.

When studying 2,128 motor vehicle accident patients, Baker et al (1974) found that mortality increases disproportionately with multiple site injuries. They discovered that squaring the AIS scores for the three most severely injured body areas resulted in an accurate portrayal of mortality expectations. For example, if a patient sustains a major laceration of the liver (a score of 5), a simple rib fracture (a score of 2), a cervical spine fracture without cord involvement (a score of 3), and a laryngeal fracture with airway obstruction (a score of 4), his/her ISS would be the sum of the three highest squared scores:  $(5 \times 5 = 25) + (4 \times 4 = 16) + (3 \times 3 = 9)$  for a total score of 50. (See Appendix G) The researcher calculated the ISS for each subject, based on the injuries listed in patients' discharge summaries in the hospital records.

## Glasgow Outcome Scale (GOS)

Developed by Jennett et al. (1981), the GOS provides five outcome categories for major trauma survivors: death, persistent vegetative state (PVS), severe disability, moderate disability, and good

recovery. Vegetative patients make no meaningful responses to their environment, although they can swallow, breathe spontaneously, have spontaneous eye opening, and exhibit reflex responses to painful stimulí.

Patients with severe disability can interact with their environment, but need help with daily living activities. They can experience either physiological deficits, neurological deficits, or both. Jennett et al. called them a "conscious but dependent" group (1981 p. 286). Those with neurological deficits cannot make rational judgments or be left without supervision. Those with physiological deficits require assistance with one or more regular activities of daily living, such as getting dressed, bathing, or eating.

Patients with moderate disability are "independent but disabled" (Jennett et al., 1981 p. 286). These patients have some limitations in their post-trauma abilities--socially, at work, or with self-care. They can have meaningful interactions, but do not return to full pre-morbid states because of minor mental or physical deficits.

Good recovery patients have the necessary capabilities to return to their pre-morbid lifestyles. They may return to previous social, professional, or job interactions, even with minor physical or neurological deficits. The researcher calculated the GOS for each patient, based on information included in patients' discharge summaries in the hospital records (see Appendix H for the GOS chart).

## Functional Independence Measure (FIM)

Developed by the Uniform Data System for Medical Rehabilitation (Hamilton et al., 1987) as a functional assessment scale for multiple disabilities, the FIM evaluates 18 items of function in self-care, mobility, communication, sphincter control, locomotion, and social cognition. The self-care area includes eating, grooming, bathing, dressing upper body, dressing lower body, and toileting. The sphincter Control category includes both bladder management and bowel management. The mobility designation includes the use of a bed, chair, or wheelchair; toilet; and tub or shower. The locomotion area includes how well patients walk or if they use a wheel chair and whether they can navigate stairs. Communication includes comprehension and expression. The final item, social cognition, includes social interaction, problem solving, and memory. For each item, the researcher entered a score on a Likert scale, from 7--complete independence-- to 1--total assistance required, based on observation of patient function. The poorest score is 18 and the best score is 126.

Most rehabilitation facilities in the United States use the FIM. A modified version was used to compare discharge status in a recent study from the Major Trauma Outcome Study data base (Gennarelli et al., 1994). However, Gennarelli et al. did not provide criteria by which other researchers could replicate their method. Therefore, this study used the original FIM. Interrator reliability rates are 86 to 97% (Hamilton, Laughlin, Granger, & Kayton, 1991). (See Appendix I for a sample FIM form that shows the six areas and the point breakdown.) The FIM was administered to major trauma patients in stratified groups of randomly sampled cohorts at 6 months to 1 year, 2 years, 3 to 4 years, and 5 years post-trauma.

## Health and Daily Living Adult Form B (HDL-B)

The copyrighted HDL-B instrument (Moos, et al., 1986) can be administered as a questionnaire or an interview. It examines personal and environmental life stressors, and the social resources and coping skills that influence adaptation. The first section of the HDL-B has 6 demographic questions, while the second section addresses employment history using 5 multiple choice questions. Sections three and four address physical and mental health concerns in 31 Likert scale, multiple choice, or fill-in-the-blank questions. The fifth section, addressing events in the past year, has 30 multiple choice questions. Section six has 12 Likert scale and multiple choice questions that address friends and family. The seventh and final section addresses home and children using 7 fill-in-the-blank, multiple choice and Likert scale questions. The HDL-B is scored by summing the answers from each item in each of the sections. (See Appendix J approval to use the HDL-B.) The researcher attempted to call each surviving major trauma patient/family to solicit dyads willing to fill out the HDL-B questionnaire. She mailed the HDL-B to post- trauma patients and a significant other for completion.

## Research Design

During phase one, the researcher conducted a retrospective review of the 1991 to 1996 air ambulance dispatch log to identify helicopter-transported patients with major trauma. After identifying the patients, the researcher obtained data from the air ambulance copies of the patients' Utah State EMS reports, including the initial GCS score and survival-to-facility data. The researcher then calculated the RTS scores for patients before 1996, based on the GCS and vital sign data included in the EMS reports. She recorded the 1996 RTS scores as they were written in the EMS reports.

During phase two, the researcher obtained the financial charges and institutional cost data for all helicopter-transported major trauma patients from 1991 to 1996 from the financial records office at the trauma center. The researcher also reviewed all helicopter-transported major trauma patients' medical records and discharge summaries to determine which patients died during acute care and which patients survived to be discharged. She used the discharge data's list of injuries and functional status to determine the ISS and GOS for each patient.

For phase three, the researcher attempted to contact all surviving patients helicopter-transported after major trauma to solicit participant dyads (patient and one family member) for the HDL-B questionnaires. She explained the aims of the study, the potential risks, and the benefits, including the right to withdraw at any time without jeopardy to future treatment. She assured potential participants that confidentiality and anonymity of data would be preserved by using code numbers only and by grouping data analysis, interpretation, and dissemination. She informed the potential participants that they might be selected for the FIMs assessment and qualitative interview. After answering any questions from the potential participants, the researcher sent each dyad who agreed to participate consent forms (see Appendices C and D for patient and significant other consent forms) and HDL-B questionnaires to

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complete and return, via prepaid envelopes. The researcher selected a stratified sample of these participants for phase four.

During phase four, data for the stratified random sample was collected from the subset of participants completing the HDL-B in cohort groups of 6 months to 1 year, 2 years, 3 to 4 years and 5 years post-trauma, as discussed in the section describing participants. The researcher then evaluated each patient in the stratified random sample using the FIM. Qualitative data were acquired at the same time, from the patient and family member, through open-ended questions that addressed psychosocial and financial concerns (see Appendix I). Each combined FIM evaluation and interview took approximately one and a half hours. The researcher conducted the FIM evaluation and interviews in a location of the participants' choice.

During the interviews, the researcher wrote brief notes and audio tape-recorded discussions for later transcription. Using a grounded theory and field research design, the following general questions were asked of the participants: a) Tell me what it has been like to be (to care for) a trauma patient? b) If you had it to do over, what would you have done differently? c) What positive things have you experienced? d) What negative things have you experienced? e) Tell me about the financial impact this experience has had for you. f) What would be your advice to others in a similar circumstance? g)How would you describe your quality of life pre-trauma and post-trauma? The last question was asked after showing the patient/significant other the definition of quality of life. The researcher used these initial probes for unstructured interviews to determine patient/family perceptions of the psychosocial costs of trauma. The investigator allowed the participants to steer the interviews to events that were meaningful to them.

Raw data from each participant/family member dyad were numerically coded, with item *a* being the patient and item *b* being the family member. The researcher maintained a key to the code numbers, raw data, and consents in a locked file in her office, separate from all other study materials. Following each interview, raw data were promptly loaded into the computer used for this research, and the original pages of raw data were stored in the locked file.

## Statistical Analysis

#### Descriptive Statistics for Demographic Data and Sources of Reimbursement (pavers) for Trauma Care

Since demographic information such as age and gender is nominal data, it was recorded as categories. The GCS, RTS, ISS, and GOS scores are ratio data; a) the categories are mutually exclusive, b) the data have a logical order, c) the categories are scaled correspondingly, d) equal differences exist between categories, and e) there is a true zero, or absence of the characteristics of any category (Hinkle, et al., 1994, p. 14-15). Univariate analyses (Munro & Page, 1993, p. 6-7) provided frequency distributions for age, gender, GCS, RTS, ISS, and GOS. Univariate analysis was also used to describe the institutional charges and who paid the financial charges for trauma care--the patient, insurers, or society.

## Nonparametric Satistics for comparison of Discharge Status with GCS, RTS, and ISS

Chi Squared, a nonparametric test was used to compare GCS, RTS, and ISS with outcome data (died in the ED, died during acute care, or survived), as measured by the GOS, since the parametric assumptions of normality and homogeneity of variance were not met by the data (Hinkle et al., 1994, p. 534). There were more deaths at poorer scores and more good recovery with higher scores.

## One-way Analysis of Variance (ANOVA) Comparing Financial Charges and Institutional Costs with the GCS, RTS, ISS, and GOS

One-way ANOVA was used to determine differences in means for financial charges and institutional costs. This statistic was selected because the assumption of a normal distribution was violated by behavior for GCS, RTS, ISS, and GOS (Munro & Page, 1993, p. 102) and distribution of the dependent variables (financial charges and institutional costs) was skewed. In addition, there was a nonlinear relationship between the dependent variables (financial charges and institutional costs) and the covariates (GCS, RTS, ISS, and GOS) (Hinkle et al., 1994, p. 500). ANOVA is the sum of the squares within groups and between groups. Homogeneity of variance assumes that variance for one group is equal to variance in another group, such as categories within GCS, RTS, ISS, and GOS when compared to financial costs. ANOVA partitions the total variation into components of explained and unexplained variation, calculates the variance of each component, and uses the ratio of the two variances as the test statistic. Additionally, the ANOVA procedure is robust and powerful; a positive F value is relatively unaffected by heterogeneity of variance (Hinkle et al., 1994, p. 322-328, 337).

Pearson's r, which measures linear relationships, was used for analysis of the dependent variables (financial charges and institutional costs by length of stay cost) (Hinkle et al., 1994 p. 112-115), since there was a strong correlation between financial charges (r = .89), institutional costs (r = .91), and length of stay.

## **Qualitative Analysis**

Immediately after each interview, the researcher wrote observational notes (ON) describing the surroundings of the participants and recapitulated her interactions with them. She analyzed the interview contents via constant comparative analysis (Strauss & Corbin, 1990) after transcribing each tape recording and reviewing her notes. Focusing on the participants' words, the researcher developed categories through open coding. During open coding, she watched for in-vivo coding (explicit codes stated by the participants, themselves). Using axial coding, she scrutinized the data for emerging patterns or patterned differences, recurring themes, and repeated relationships to cluster the initial categories. The researcher selected core categories that encapsulated and integrated the relationships found through selective coding. Throughout analysis, the researcher repeatedly evaluated the process to ensure theoretical sensitivity. An experienced consultant examined selected data and provided feedback as to recurrent patterns and themes. Additionally, a dissertation committee member also reviewed data to assess patterns, recurring themes, and clusters.

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## Chapter 4

## Results

The purpose of this triangulated descriptive study was threefold: (a) to identify the financial costs for acute trauma care (including financial charges and institutional costs for those who die in the emergency department, those who die early in treatment, and those who survive to be discharged) and who pays those charges; (b) to identify the relationship between financial charges/institutional costs and severity of injury; and (c) to identify survivor functional costs and psychosocial costs, or quality of life, for patients and families, not only by current health care outcome criteria, but also from patients' and families' perspectives. The study utilized the Glasgow Coma Scale (GCS), the Revised Trauma Score (RTS), and the Injury Severity Score (ISS) to determine severity of injury and the Glasgow Outcome Score (GOS) to identify survivor functional outcome at discharge. The study utilized the Functional Independence Measure (FIM) to identify patients' current level of function, and the Health and Daily Living Form B (HDL-B), for patients and family members to identify psychosocial outcomes. The researcher also utilized a grounded theory approach to discover patients' and family members' perceptions of their psychosocial outcomes and quality of life.

There were four phases to the study. Phase one included identification of the major trauma patients and their initial severity of injury using the GCS (see Appendix E) and the RTS (see Appendix F). In phase two, the full extent of injury was determined, using the ISS (see Appendix G); physical outcome at discharge from the acute care setting was measured using the GOS (see Appendix H), and the financial charges and costs for trauma care were calculated. Phase three involved determining psychosocial outcomes for major trauma patients and family members using the HDL-B (see Appendix J). Phase four was used to examine present physical and psychosocial outcomes for the major trauma patients using the

FIM and psychosocial outcomes for patients and their families through qualitative interviews (see Appendix I).

## Data Collection

## Phase 1

After receiving approval from the University of San Diego's Committee on the Protection of Human Subjects and LDS Hospital's Research and Human Rights Committee (see Appendices A and B) in August of 1996, the researcher reviewed Life Flight's air ambulance dispatch log, which was kept in the Life Flight dispatch office. Assisted by one of two research assistants, the researcher identified major trauma patients (Level 1) injured from 1991 through August of 1996. As one person read the data from the dispatch log, the other entered it into a computer spreadsheet program (Quatro Pro) on a computer provided in the Life Flight office. The data included patients' names, identification numbers, and the dates of their accidents. The researcher and assistants periodically reviewed their work to detect any errors and correct them. A total of 431 major trauma patients were identified.

For each of the 431 patients, the researcher and assistants gathered GCS, RTS, and vital sign data from the air ambulance copies of the Utah State EMS reports, kept in the Life Flight archives. The researcher obtained the RTS for patients injured in 1996 and calculated the RTS for patients injured prior to 1996, when the RTS became the standardized triage score in Utah. The RTS was calculated from the GCS and vital sign data (blood pressure and respiratory rate) included in the EMS reports. The researcher and assistants practiced calculating RTS on the 1995 and 1996 patients, verifying their accuracy by comparing their scores with the actual RTS given by the Life Flight nurses. They also discussed the RTS with Life Flight nurses to validate the scoring procedure.

Four of the 431 patients had no GCS, and no RTS could be calculated for them. One patient did not have vital sign data recorded to use in calculating the RTS. However, later data gathering showed those four patients with missing GCS and the five patients with missing RTS all had ISS scores and financial

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data available. Eleven patients had no Utah State EMS forms, but the forms were found in the patients' medical charts. Consequently, the researcher kept all these patients in the study.

## Phase 2

The researcher met with the trauma facility's medical records personnel and negotiated systematic access to the medical records for the 431 major trauma patients identified. The medical records personnel used the patients' Life Flight identification numbers to determine the in-hospital record numbers. Each week, personnel pulled twenty-five to fifty medical records. They were unable to find records for twenty-seven patients, who had to be dropped from the study, leaving 404 patients. The financial records office at the trauma center was unable to find Life Flight financial cost data for 34 patients, but provided the financial cost data for a total of 370 remaining helicopter-transported major trauma patients from 1991 to 1996.

The trauma facility provided an office and computer support where the researcher and her assistants could work without interruption. Each piece of data was entered directly into a Quatro Pro spreadsheet, eliminating the possibility of transcription error. Continuous dialogue and review with an assistant verified the accuracy of the data as it was entered. Additionally, after all data for the major trauma patients was entered, the researcher ran repeated descriptive analyses to find any discrepancies and to verify the accuracy of the data.

The discharge summaries contained in the medical records listed each patient's injuries and physical status at the time of discharge. The researcher and her assistants used these data to determine the ISS and GOS for each patient. The researcher also reviewed the major trauma patients' hospital medical records and discharge summaries to determine which patients died in the ED, which died during acute care and which patients survived to be discharged. There were 28 patients who died in the ED, 53 who died during acute care, and 286 survivors, with three patients whose discharge status could not be identified.

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Additionally, the medical records for the major trauma patients yielded gender, age, ethnicity, and drug and alcohol use information. They also contained addresses and telephone numbers to use for Phase Three.

## Phase 3

The researcher attempted to call all 286 survivors who were helicopter-transported to a Level I Trauma Center after major trauma to solicit participant dyads (patient and one family member) to respond to the HDL-B questionnaires. For each telephone number where there was no answer, she tried a minimum of five times. For those patients who no longer lived at that home, the researcher asked for and received the patient's new number. One patient's chart had, "DO NOT CONTACT' written on it. Out of the 286 patients, the researcher initially reached 76 patients.

For the telephone numbers that had been disconnected, the researcher looked in all the local telephone books for a new number, and checked with operator assistance for those in distant areas. Five additional patients were identified in this manner.

For those patients who could not be contacted by telephone, the researcher sent a query letter to the last known address, requesting participation. She included a postage-paid return card with a place for the patient to say, "yes, I would like to participate," or, "no, I would not like to participate." Three additional patients were identified in this manner.

With the original 76 patients who were contacted, the 5 found through telephone books, and the 3 patients who responded to the query letter, the researcher reached 84 patients (29% of the survivors). She was unable to reach 202 patients.

The researcher told patients or family members the aims of the study and described the potential risks and benefits. She explained the voluntary nature of the study and the participants' right to withdraw at any time without jeopardy to future treatment. She assured potential participants that confidentiality and anonymity of data would be preserved by using code numbers and by grouping outcomes of data analysis, interpretation, and dissemination. She informed the potential participants that they might be selected for the

FIMs assessment and qualitative interview. After answering all questions posed by potential participants, the researcher sent each dyad who agreed to participate a letter restating the aims of the study, the voluntary nature of the study and the participants' right to withdraw at any time, consent forms (see Appendices C and D ), and HDL-B questionnaires (see Appendix J) to complete and return in prepaid preaddressed envelopes.

Raw data from the HDL-B questionnaires for each participant/family member dyad were numerically coded, with item *a* being the patient and item *b* being the family member. The researcher isolated the key to the code numbers, raw data, and consents in a locked file in her office, separate from all other study materials.

Eighty patients agreed to complete the HDL-B questionnaire and four refused. For each of those who agreed to participate, but did not return the HDL-B in a timely manner, the researcher called again. Sixty-one percent of consenting patients (49 of 80) returned the HDL-B: thirty-five dyads (patient and family member), thirteen patient-return-with-no-family member, and one family-member-without-a-patient return.

## Phase 4

The researcher planned to obtain a stratified random sample of those who returned the HDL-B for subsequent interview and evaluation with the FIM. The initial plan was to recruit at least 5 persons in each group, at 6 months, 1 year, 2 years, 3 years, and 5 years post-trauma. However, there were only five major trauma patients from 1996 who returned the HDL-B, twelve from 1995, ten from 1994, seven from 1993, four from 1992, and eleven from 1991. The researcher drew numbers from a hat for 1991, 1993, and 1994 to determine which major trauma patients and families to interview. She attempted to reach all the patients who had completed the HDL-B in groups with five or fewer participants. The resulting data were then categorized into groups 6 months to 1 year, 2 years, 3 to 4 years, and 5 years post-trauma to increase statistical analysis power.

One 1992 patient made repeated appointments, but was not home each time the researcher arrived. One 1993 patient, who lived in an extended care facility, was ill at the time of the first appointment. At the time of the second appointment, his mother, the contact person had died. No further attempts were made to contact that patient. One 1996 patient was in jail and visiting privileges were not allowed. Five patients were interviewed by telephone: a 1993 patient in Pennsylvania, a 1994 patient in Massachusetts, and three 1995 patients, one in California, one in Texas, and one in Vermont. Total interviews included seventeen patient/family member dyads, three single patients, and one single family member (see Table 1).

The researcher used the FIM to evaluate the physical and psychosocial functional ability of each major trauma patient agreeing to an interview. For those who were interviewed by telephone, the interviewer asked about each FIM category. Physical function reports of patients interviewed by telephone had to be accepted as self-reported. However, the researcher validated the patients' psychosocial reports by assessing their verbal communications while discussing the qualitative questions. For those who were interviewed in person, the researcher assessed most physical functions and asked about those not immediately obvious, such as bowel and bladder control and ability to provide self care.

| <u>Injury</u> |                    | Patient | Patient & | Family |
|---------------|--------------------|---------|-----------|--------|
| Year          | Group              | Only    | Family    | Only   |
| 1991          | 5 years            | I       | 4         |        |
| 1992          | 3 to 4 years       |         | 2         |        |
| 1993          | 3 to 4 years       |         | 3         |        |
| 1994          | 2 years            | 1       | 2         |        |
| 1995          | l year             | I       | 4         |        |
| 1996          | 6 months to 1 year |         | 2         | 1      |
|               |                    |         |           |        |

| Composition of Patient/Family Dyads for Interviews $(n = 21)$ |             |                   |                  |                 |
|---|-------------|-------------------|------------------|-----------------|
|   | Composition | of Patient/Family | Dyads for Interv | rieurs (n = 71) |

Table 1

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All interviews took place at the homes of the major trauma patients, at their request. One mother asked to be present during the interview with the son. The son agreed, reluctantly. For all other interviews, the interviewer first met privately with the major trauma patient and then privately with the family member. Qualitative data were acquired at the same time, from the patient and family member through open-ended questions that addressed psychosocial and financial concerns. The combined FIM evaluation and interviews of each patient and family member took less than one and a half hours. During the interviews, the researcher wrote brief notes and, with participants' permission, audio tape-recorded the conversations for later transcription. Using a grounded theory and field research design, the following general questions were asked of the participants: (a) Tell me what it has been like to be (care for) a trauma patient? (b) If you had it to do ever, what would you have done differently? (c) What positive things have you experienced? (d) What negative things have you experienced? (e) Tell me about the financial impact this experience has had for you. (f) What would be your advice to others in a similar circumstance? (g) How would you describe your quality of life pre-trauma and post-trauma? The researcher used these initial probes for the unstructured interviews to determine patient/family perceptions of the psychosocial costs of trauma. The investigator allowed the participants to steer the interviews to events that were meaningful to them.

#### **Descriptive Statistics**

During the study period, from 1991 through August of 1996, there were 431 major trauma patients transported by helicopter to the study site. Medical records for twenty-seven patients and Life Flight financial data for thirty-four patients were not available. This left 370 patients in the study. The total billing charges for these 370 major trauma patients were \$9,945,973; actual institutional costs amounted to \$7,089,962. Over one fifth of the patients died (n = 81): 8% in the ED (n = 28) and 14% during acute care (n = 53). The eighty-one patients who died accumulated charges of \$1,257,064 and institutional costs of \$973,574. Two hundred eighty-six patients (78%) survived to be discharged, with total charges of \$8,688,909 and institutional costs of \$6,116,388. Rarely were any scoring system data missing. Therefore the remaining analysis represents all 370 patients, with notation of the missing values.

Three-fourths of the patients were male and one-fourth were female. Ages ranged from 18 to 93 years (see Table 2). Although it was not statistically significant (p = 0.522), all three of the major trauma patients who were over 75 died. There were no statistically significant differences in financial charges (p = .498) or institutional costs (p = .523) by age group. Most of the major trauma patients in this study were Caucasian, with few representatives of other ethnic backgrounds (see Table 3). This is reflective of the local population.

Eighty-eight percent of the major trauma patients had laboratory values with which to evaluate alcohol or drug use prior to injury. Fifty-nine percent showed no alcohol or drug use. Fifty-one (16%) of the patients' laboratory values showed alcohol use, thirty-three (9%) showed use of other drugs, and an additional twenty-five (7%) had used both alcohol and other drugs. Of the total 370 patients, 30% had used either drugs, alcohol, or both just prior to the accident (see Table 3). There were no significant statistical differences in injury severity (GCS [p = .993], RTS [p = .721], ISS [p = .76]), GOS (p = .816), death (p = .878); financial charges (p = .422); or financial costs (p = .395) between those who used alcohol, drugs, or both and those who did not.

Ten percent of the major trauma patients in this study (38) were victims of intentional injuries: 26 gunshot wounds and 12 stab wounds. These 38 patients had financial charges of \$687,453 and institutional costs of \$508,952. Three were suicide attempts: 2 gunshot wounds and 1 stab wound.

## Table 2

## Composition of participants by Gender and Age (n = 370)

| Gender | n   | %  | Age   | n*  | %  |
|--------|-----|----|-------|-----|----|
| М      | 281 | 76 | 18-24 | 129 | 35 |
| F      | 89  | 24 | 25-44 | 188 | 51 |
|        |     |    | 45-64 | 45  | 12 |
|        |     |    | 65-74 | 2   | 01 |
|        |     |    | 75-93 | 3   | 01 |

\*missing 3

## Table 3

|                 |          |     |               | <u> </u> |    |
|-----------------|----------|-----|---------------|----------|----|
| Ethnicity       | <u> </u> | %   | Substance Use | <u> </u> | °o |
| Caucasian       | 304      | 87  | none          | 218      | 67 |
| Hispanic        | 25       | 7   | alcohol       | 51       | 14 |
| Polynesian      | 06       | 2   | other drugs   | 33       | 10 |
| Native American | 02       | I   | both          | 25       | 7  |
| Oriental        | 03       | I   |               |          |    |
| Vietnamese      | 03       | 1   |               |          |    |
| Japanese        | 01       | 0.3 |               |          |    |
| English         | 01       | 0.3 |               |          |    |
| Afro-American   | 01       | 0.3 |               |          |    |
| German          | 01       | 0.3 |               |          |    |
| Russian         | 01       | 0.3 |               |          |    |
|                 |          |     |               |          |    |

Composition of Participants by Ethnicity (n = 348) and Substance Use (n = 327)

## Statistical Analysis

The statistical analysis presented, addresses each research question. An alpha level of .05 was used to determine significance of findings for all statistical tests.

Two factors must be addressed when exploring the economic costs of major trauma: *charges* are the amount for which the major trauma patient or payment source is billed; *costs* are the amount that represents the hospital's expenditures in providing care for the major trauma patient. The financial charges data include Life Flight financial data, such as transport time, equipment, and personnel, as well as hospital charges for daily room rates, procedures, treatments, and equipment. To avoid confusion during discussion, tables will present data for both financial charges and institutional costs: since the major concern for this study was society's cost, not institutional costs, the discussion addresses only financial charges. Trends for both amounts are similar, although charges are usually larger than institutional costs. In limited instances, usually for patients who died, the institution did not charge the full amount of costs.

## Research Question 1

What are the differences between financial charges and institutional costs for major trauma patients who die in the emergency department and patients who die in the acute care setting?

Twenty-eight patients died in the ED and fifty-three died during acute care. After examining a scatter plot that determined nonlinearity for the data, financial charges and financial costs for major trauma patients who died in the ED and those who died in the acute care setting were analyzed via one-way analysis of variance (ANOVA), with significant F levels, and <u>p</u> values of .0004 for both charges and institutional costs. The summaries of one-way ANOVAs for major trauma patients who died are shown in Tables 4 and 5. Means, standard deviations, ranges, and length of stay (LOS) are shown in Table 6, with graphic portrayal of the results in Figures 2 and 3.

#### Table 4

Summary ANOVA: Financial Charges for Patients who Died in the Emergency Department (ED) versus Those who Died in Acute Care

| Source        | df | SS        | MS        | F    | p      | <br> |
|---------------|----|-----------|-----------|------|--------|------|
| ED/Acute Care | 2  | 4.350E+09 | 2.175E+09 | 8.74 | 0.0004 |      |
| Error         | 78 | 1.941E+10 | 2.488E+08 |      |        |      |
| Total         | 80 | 2.376E+10 |           |      |        |      |

Patients who died during acute care had significantly higher financial charges than those who died in the emergency department. Major trauma patients who died in the ED had mean financial charges of \$5.622 per person. Those who died during acute care had mean financial charges of \$20,509. Ranges for both groups varied widely, from \$1,272 to \$16,545 in the ED compared with \$2,807 to \$117,058 during acute care.

Major trauma patients in the ED receive a broad range of care, from massive resuscitation efforts which may include open chest or abdominal surgery in the trauma room, to pronouncement of death shortly after arrival. For example, the patient whose financial charges were \$1,272 had a GCS of 3 and an RTS of 0 as (s)he arrived in the trauma room, with no possibility of survival (ISS of 75). The hospital chose to eliminate all charges, except the actual Life Flight cost for the patient (R. Campbell, personal communication, February, 1998.)

Major trauma patients who die during acute care may have very severe injuries that require major resuscitation efforts and numerous surgeries. They may receive a multitude of treatments, yet die from complications after an extended period of time, or they may die soon after admission. The patient with a financial charge of \$2,807 arrived at the hospital as the result of a gunshot wound. (S)he had a GCS of 3, a RTS of 3, an ISS of 75, received no surgery, computerized tomography, or magnetic resonance imaging. and died during the first day. The patient with a financial charge of \$117,058 had a severe head injury

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## Table 5

## Summary ANOVA: Institutional Costs for Patients who Died in the Emergency Department (ED) versus

| ··            |    |           |           |       |        |
|---------------|----|-----------|-----------|-------|--------|
| Source        | df | SS        | MS        | F     | p      |
| ED/Acute Care | I  | 1.675E+09 | 1.675E+09 | 16.74 | 0.0004 |
| Error         | 79 | 7.906E+09 | 100076652 |       |        |
| Total         | 80 | 9.581E+09 |           |       |        |
|               |    |           |           |       |        |

Those who Died in Acute Care

with a GCS of 8, an RTS of 8, and an ISS of 75. (S)he went to Computerized Axial Tomography (CT), required surgery, and stayed in the hospital 34 days before dying. Pearson's r for financial charges and length of stay (LOS) was .89. Pearson's r for financial costs and LOS was .91.

In summary, as indicated in Figures 2 and 3, patients who died in the ED had significantly lower mean financial charges and institutional costs than patients who died during acute care. Lower charges are related to fewer treatments and a decreased LOS.

## Table 6

Mean Financial Charges and Mean Institutional Costs (SD, Ranges, and Length of Stay [LOS]) for Patients who Died in the Emergency Department (ED) versus Those who Died in Acute Care,

|               | Mean       |           |         | Mean              |             |         |                  |           |
|---------------|------------|-----------|---------|-------------------|-------------|---------|------------------|-----------|
|               |            | Financial |         | i                 | nstitutiona | al      |                  |           |
| ED/Acute      | <u></u> n* | Charges   | SD      | Ranges            | Costs       | SD      | Ranges L         | <u>os</u> |
| Died in ED    | 28         | \$5,622   | \$5,923 | \$1,272-\$165,545 | \$5,872     | \$4,025 | \$2,414 - 19,219 | 1         |
| Died in Acute | 53         | 20,978    | 19,148  | \$2,807- 117,058  | 15,094      | 11,985  | 2,388 - 72,540   | 3.5       |

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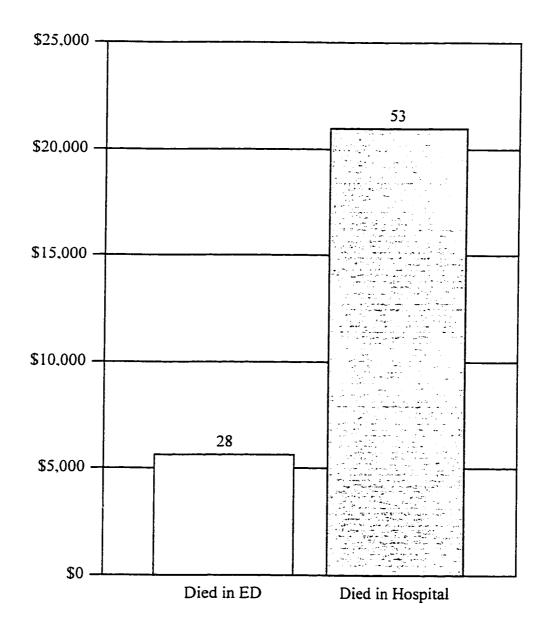


Figure 2. Mean financial charges for patients who died in the Emergency Department (ED) and those who died during acute care.

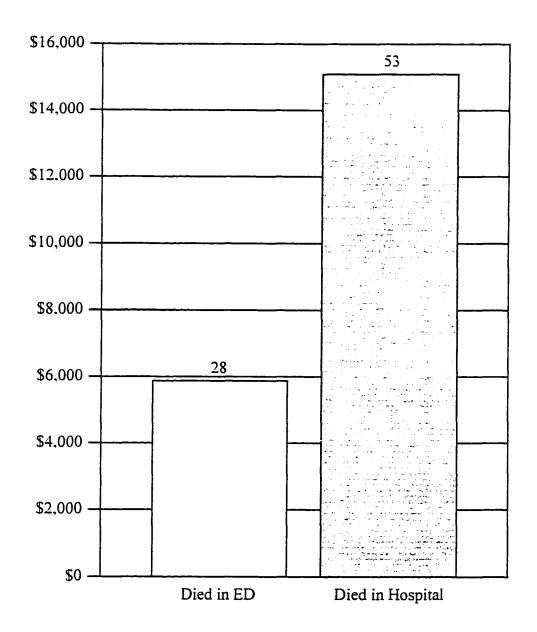


Figure 3. Mean institutional costs for patients who died in the Emergency Department (ED) versus those who died during acute care.

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## Research Ouestion 2

What are the differences between financial charges and institutional costs for major trauma patients who die and for those who survive?

There were 81 patients who died (22%), 286 who survived (78%), and 3 whose status could not be determined. After a scatter plot was examined to determine nonlinearity for the data, one-way ANOVAs were applied for financial charges and institutional costs of major trauma patients who died or survived. The results provided significant F levels, with p values of 0.0009 and 0.0007, respectively (see Tables 7 and 8). Mean financial charges for all those who died were \$15,519 and mean financial costs were \$12,019. For those who survived, the mean financial charges were \$30,295 and mean financial costs were \$21,301. As Table 9 and Figures 4 and 5 show, those who died had significantly lower financial costs than those who survived. Reasons for variations in charges for major trauma patients who died were addressed in question one.

## Table 7

|  |  | ليبري بواعاتمان ومتلاحمانية ويها بيوي ويرجد وبرجي ويرجد |  |
|--|--|---|--|
|  |  |   |  |
|  |  |   |  |

Summary ANOVA: Financial Charges for Patients who Survived versus Those who Died

| Source        | df  | SS        | MS        | F     | <u>p</u> |
|---------------|-----|-----------|-----------|-------|----------|
| Survived/Died | I   | 1.378E+10 | 1.378E+10 | 11.15 | 0.0009   |
| Error         | 365 | 4.511E+11 | 1.236E+09 |       |          |
| Total         | 366 | 4.649E+11 |           |       |          |

## Table 8

## Summary ANOVA: Institutional Costs for Patients who Survived versus Those who Died

| Source        | df  | <u>SS</u> | MS        | F     | p      |
|---------------|-----|-----------|-----------|-------|--------|
| Survived/Died | 1   | 5.439E+09 | 5.439E+09 | 11.70 | 0.0007 |
| Error         | 365 | 1.697E+11 | 464812298 |       |        |
| Total         | 366 | 1.751E+11 |           |       |        |

Survivors may have many major injuries that are not life threatening, but require extended care, or they may have complications that use numerous resources and lengthen their hospital stay. In this study, ranges varied widely due to LOS, initial severity of injuries, and the ensuing complications. For example, the patient who had financial charges of \$416,036 also had Life Flight charges of \$5,600. (S)he had no head injury, hence a GCS of 15. (S)he had an RTS of 12, and an ISS of 35, but required emergent surgery to control abdominal bleeding. The patient developed numerous life-threatening complications that resulted in a fifty-nine day LOS, with repeated surgeries and extensive treatments. In contrast, the patient who had financial charges of \$2,752 also had a GCS of 15, and an RTS of 12, but required no treatments and stayed less than one day.

In summary, patients who died had statistically significantly lower financial charges and institutional costs than those who survived, related to shorter LOS and decreased utilization of health care resources. Patients who died had a mean LOS of 2.8 days, while patients who survived had a mean LOS of 8.3 days (p = <.0001).

## Table 9

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# Mean Financial Charges and Mean Institutional Costs (SD, Ranges, and Length of Stay [LOS]) for Patients who Survived versus Those Who Died

|           |     | Mean      |           |                   | Mean             |           |            |         |      |
|-----------|-----|-----------|-----------|-------------------|------------------|-----------|------------|---------|------|
|           |     | Financial | I         | I                 | Institutiona     | al        |            |         |      |
| Level     | nª  | Charges   | <u>SD</u> | Ranges            | Costs            | <u>SD</u> | Range      | 5       | LOS_ |
|           |     |           |           |                   |                  |           |            |         |      |
| Survived  | 286 | \$30,295  | \$38,723  | \$2,752-\$416,036 | <b>\$</b> 21,301 | \$23,721  | \$3,281-\$ | 241,843 | 8.3  |
| Died      | 81  | 15,519    | 17,233    | 1,272 -117,058    | 12,019           | 10,774    | 2,388      | 72,540  | 2.8  |
| * missing | 3   |           | <u> </u>  |                   |                  |           |            |         |      |

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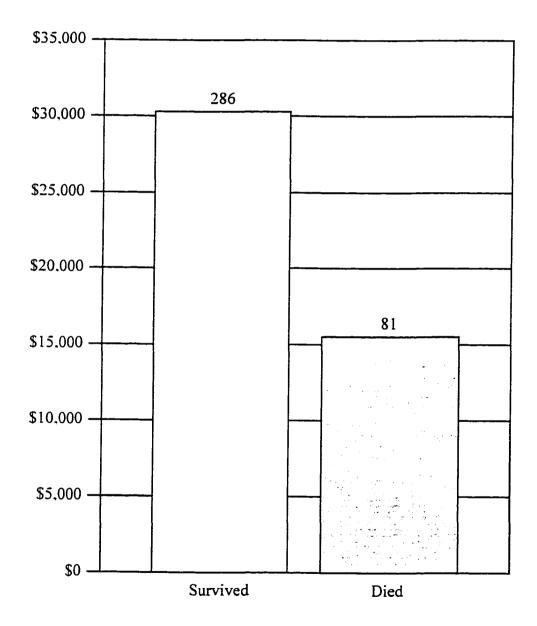


Figure 4. Mean financial charges for patients who survived and those who died.

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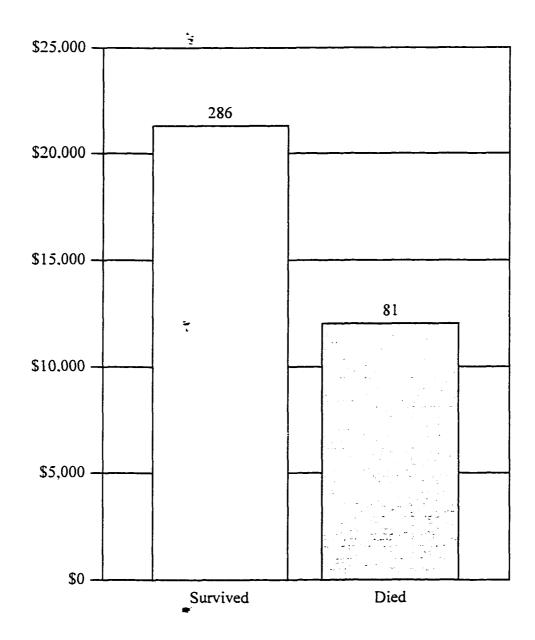


Figure 5. Mean institutional costs for patients who survived and those who died.

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#### Research Ouestion 3

What is the relationship between financial charges and institutional costs and severity of injury as assessed by initial Glasgow Coma Score (GCS)?

The GCS is a field triage score that indicates the initial level of consciousness for major trauma patients. After examining a scatter plot that determined nonlinearity for the data, scores for the GCS, financial charges, and financial costs were analyzed using one-way ANOVAs, which provided significant F tests and p values of 0.0111 and 0.008, respectively. The summaries of ANOVAs for the GCS are shown in Tables 10 and 11.

As Table 12 and Figures 6 and 7 show, and t-tests revealed (p = 0.0226), those major trauma patients with GCS scores of 3 and 5 had significantly lower financial charges than those with GCS scores of 4, 6, 7, and 8. GCS scores of 13, 14, and 15 also had significantly lower charges than GCS scores of 4, 6, 7, and 8 (p = 0.035).

Table 10

| Source | df  | \$\$      | MS        | <u> </u> | р      |
|--------|-----|-----------|-----------|----------|--------|
| GCS    | 12  | 3.239E+10 | 2.699E+09 | 2.20     | 0.0111 |
| Error  | 352 | 4.324E+11 | 1.228E+09 |          |        |
| Total  | 364 | 4.648E+11 |           |          |        |

| Summary ANOVA: Patients' I | Financial Charges | by Glasgow ( | Coma Scale (GCS) |
|----------------------------|-------------------|--------------|------------------|
|                            |                   |              |                  |

| Source | df  | SS        | MS        | F    | p      |
|--------|-----|-----------|-----------|------|--------|
| GCS    | 12  | 1.265E+10 | 1.054E+09 | 2.29 | 0.0080 |
| Егтог  | 352 | 1.623E+11 | 460973319 |      |        |
| Total  | 364 | 1.749E+11 |           |      |        |

Summary ANOVA: Patients' Institutional Costs by Glasgow Coma Scale (GCS)

Most of the major trauma patients studied here fell into two categories within the GCS, the best and the worst scores, 15 and 3. One hundred twenty (33%) of the patients had an initial GCS of 15--able to open eyes spontaneously, able to speak normally, and able to follow commands. Fifty-eight (16%) were those with the most severe head injuries, a GCS of 3--unable to open eyes, unable to speak, and unable to respond to commands. See Table 12 for the frequencies, mean charges, mean costs, standard deviations, ranges, and mean LOS for each GCS score.

As one looks at Figures 6 and 7, GCS scores of 3 and GCS scores of 15 clearly had similar charges (means of \$23,057 and \$25,353, respectively). However, their mean LOS differed. Those with GCS scores of 3 (81% of whom died) utilized more treatments and procedures in a shorter period of time, whereas those with GCS scores of 15 required treatments, procedures, and observation over a longer period of time.

Of the 58 major trauma patients with GCS scores of 3, 47 (81%) died; 24 in the ED and 23 during acute care. Mean financial charges for patients with GCS scores of 3 were \$23,057, with ranges from \$1,272 to \$248,685. As stated in question one, the patient whose financial charges were \$1,272 was in traumatic full arrest as (s)he arrived in the trauma room, with no possibility of survival. The patient whose financial charges were \$248,685 had a 69 day LOS, the longest LOS in the study, and required numerous health care resources.

# Patients' Mean Financial Charges and Mean Institutional Costs (SD. Ranges, and Length of Stay [LOS]) by Glasgow Coma Scale (GCS).

|            |           | Mean             |          |                    | Mean         |          |                    |      |
|------------|-----------|------------------|----------|--------------------|--------------|----------|--------------------|------|
|            |           | Financial        |          | I                  | Institutiona |          | Mean               |      |
| <u>GCS</u> | <b>n*</b> | Charges          | SD       | Ranges             | Costs        | SD       | Ranges             | LOS  |
| 3          | 58        | <b>\$</b> 23,057 | \$44,397 | \$1,272 -\$248,685 | \$16,760     | \$27,848 | \$2,388 -\$151,255 | 5.4  |
| 4          | 13        | 47,664           | 36,896   | 7,313 - 121,784    | 32,031       | 22,957   | 6,421 - 75,459     | 11.8 |
| 5          | 9         | 28,426           | 23,667   | 10,506 - 83,844    | 20,152       | 14,061   | 8,061 - 50,728     | 5.0  |
| 6          | 17        | 47,940           | 43,159   | 13,965 -194,735    | 32,299       | 26,457   | 10,578 - 121,057   | 9.2  |
| 7          | 14        | 43,582           | 27,831   | 10,085 -101,612    | 29,911       | 17,781   | 7,026 - 68,452     | 11.8 |
| 8          | 13        | 45,289           | 27,715   | 10,926 -117,058    | 30,252       | 16,591   | 10,489 - 72,540    | 10.6 |
| 9          | 9         | 30,508           | 22,423   | 10,154 - 79,714    | 21,218       | 14,883   | 8,875 - 55,258     | 9.9  |
| 10         | 6         | 47,675           | 39,574   | 11,960 -121,312    | 31,170       | 23,364   | 9,289 - 73,050     | 11.3 |
| 11         | 6         | 22,793           | 3,968    | 18,362 - 29,133    | 16,494       | 2,129    | 12,952 - 18,722    | 6.3  |
| 12         | 16        | 23,767           | 15,027   | 7,181 - 54,708     | 17,446       | 10,292   | 6,602 - 41,649     | 5.9  |
| 13         | 34        | 17,327           | 9,217    | 6,560 - 50,185     | 12,864       | 6,000    | 4,246 - 34,416     | 4.9  |
| 14         | 49        | 18,119           | 18,167   | 3,073 - 93,101     | 13,385       | 11,448   | 3,730 - 59,840     | 5.4  |
| 15         | 121       | 25,351           | 42,443   | 2,752 -416,036     | 18,521       | 25,487   | 3,281 - 20,599     | 7.2  |

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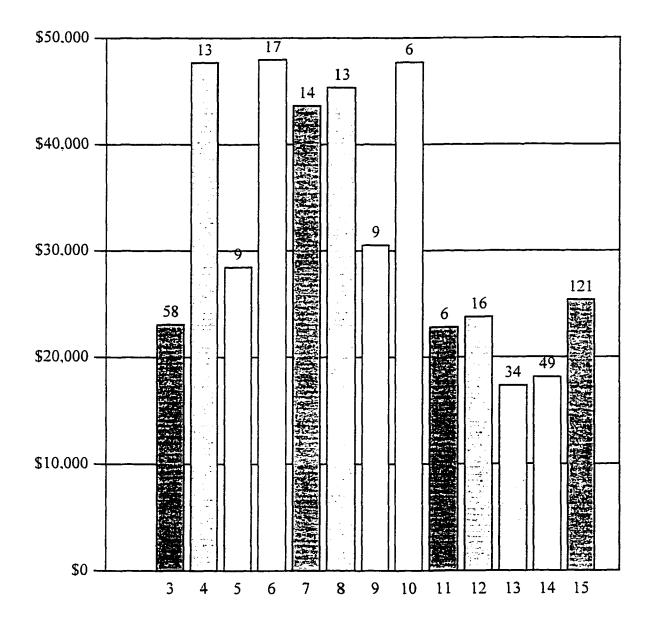


Figure 6. Patients' mean financial charges by Glasgow Coma Scale (GCS).

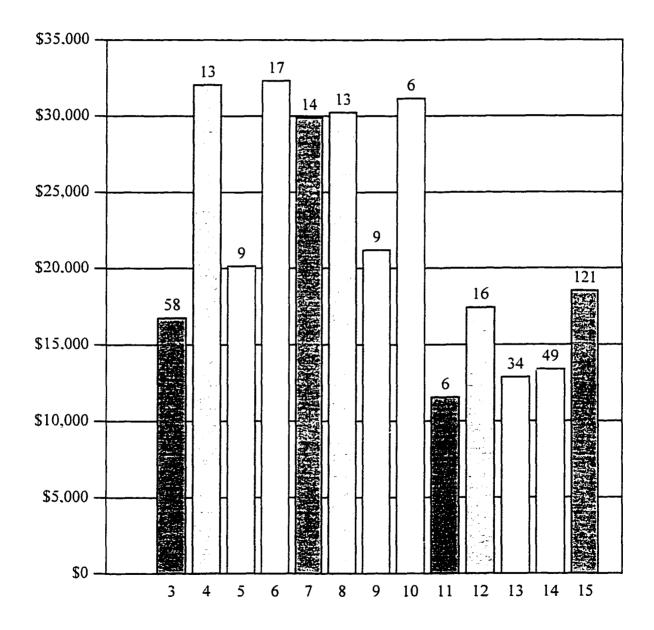


Figure 7. Patients' mean institutional costs by Glasgow Coma Scale (GCS).

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Of the other severely head-injured patients (GCS less than 9), those with a GCS of 5 also cost significantly less than did those with GCS scores of 4, 6, 7, and 8. Only nine patients had GCS scores of 5, with a narrower range and a smaller standard deviation for financial costs, in contrast to others in the adjacent GCS groups with severe head injury which may partially account for the difference in financial charges for the GCS 5 group. They also had lower mean LOS (5 days).

The six patients with GCS scores of 10, had much larger standard deviations than the patients scoring to either side, which may partially account for the higher financial charges for GCS 10 scores. These major trauma patients had a mean LOS of 11.3 days.

Financial charges for all GCS scores ranged from \$1,272 for the patient with a GCS score of 3 to \$416,036 for a patient with a GCS of 15. As stated in regard to question two, the patient whose financial charges were \$416,036 had no head injury, but required emergent surgery to control abdominal bleeding. Numerous other life-threatening complications later developed, resulting in a fifty-nine day acute hospital stay, with repeated surgeries and extensive treatments.

In summary, financial charges and institutional costs were similar for patients who had severe head injuries and mild head injuries, whereas patients with moderate head injuries incurred higher financial charges and institutional costs. That is, more of the patients with severe head injuries died in the ED or early in acute care, and patients with moderate head injuries had longer LOS and required more health care resources.. In contrast, patients with mild head injuries required fewer treatments and shorter LOS than patients with moderate head injuries.

#### Research Question 4

What is the relationship between financial charges and institutional costs and severity of injury as assessed by initial Revised Trauma Score (RTS)?

The RTS is a field triage score that can indicate the need for a trauma patient to go to a Trauma Center. It incorporates coded values for GCS, blood pressure, and respiratory rate. After examining a scatter plot that determined nonlinearity for the data, scores for the RTS and institutional financial charges and costs were analyzed using one-way ANOVAs, which provided significant F values and p values of 0.0013. and 0.001, respectively. The summaries of ANOVAs for the RTS are shown in Tables 13 and 14. As Figures 8 and 9 show, and t-tests revealed (p = < .05), financial charges for major trauma patients with RTS scores of 0 (there were no RTS scores of 1) were significantly less than those with all other RTS scores, except 2 and 12. See Table 15 for the frequencies, mean charges, mean costs, standard deviations, ranges, and mean LOS for each RTS score. The patients who had RTS scores of 3 through 11 had much higher LOS and, consequently, higher financial charges.

Of the 27 major trauma patients who arrived with RTS scores of 0, 20 died in the ED, utilizing few health care resources, and 5 died in the hospital. All 27 patients with RTS scores of 0 had GCS scores of 3. They all had ISS scores of 75, except the two who survived. One of the survivors had financial charges of \$154,438. (S)he had a LOS of 37 days, and utilized large amounts of health care resources, including surgery, CT, magnetic resonance imaging (MRI ), and angiograms.

Table 13

| Source | df  | SS        | MS        | F    | p      |
|--------|-----|-----------|-----------|------|--------|
| RTS    | 11  | 3.783E+10 | 3.439E+09 | 2.85 | 0.0013 |
| rror   | 352 | 4.254E+11 | 1.208E+09 |      |        |
| Total  | 363 | 4.632E+11 |           |      |        |

Summary ANOVA: Patients' Financial Charges by Revised Trauma Score (RTS)

| Source | df  | SS        | MS        | F    | _ p    |
|--------|-----|-----------|-----------|------|--------|
| RTS    | 11  | 1.451E+10 | 1.319E+09 | 2.90 | 0.0010 |
| Error  | 352 | 1.600E+11 | 454426296 |      |        |
| Total  | 363 | 1.745E+11 |           |      |        |

| Summary ANOVA: | Patients' Institutional | Costs According to | Revised Trauma Score (RTS) |
|----------------|-------------------------|--------------------|----------------------------|
|                |                         |                    |                            |

Only one patient had an RTS score of 2. That patient died in the ED, with a charge of \$5,266. The majority (184) of the patients had an initial RTS of 12--a GCS of 13-15, a systolic blood pressure greater than 89 mm. Hg., and a respiratory rate of 10-29 breaths per minute. Their mean financial charge was \$10,572 with a mean LOS of 5.8 days.

In summary, and in contrast to the GCS category in which most patients who were severely injured died, there were deaths recorded throughout the RTS scale. Consequently, there were no statistically significant differences in financial charges for any of the scores, except the highest and lowest.

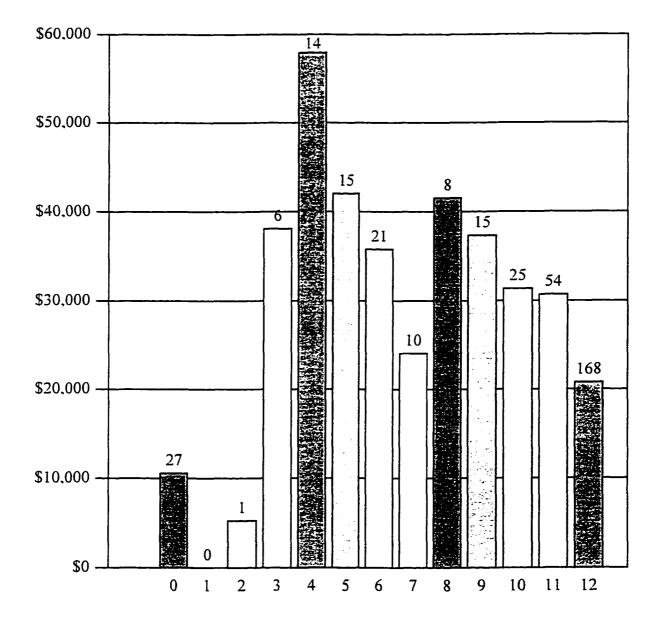


Figure 8. Patients' mean financial charges by Revised Trauma Score (RTS).

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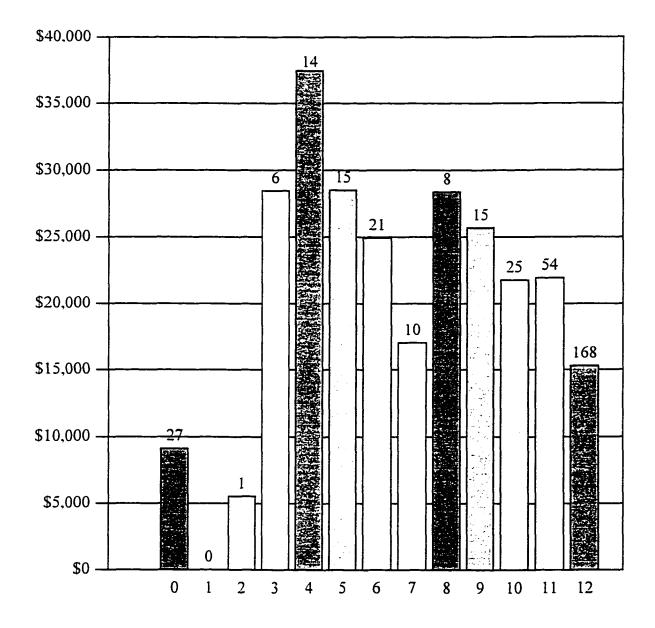


Figure 9. Patients' mean institutional costs by Revised Trauma Score (RTS).

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# Patients' Mean Financial Charges and Mean Institutional Costs (SD, Ranges and Length of Stay [LOS]) by Revised Trauma Score (RTS)

|           |             | Mean     |          |                    | Mean          |          | · · · · · · · · · · · · · · · · · · · |      |
|-----------|-------------|----------|----------|--------------------|---------------|----------|---------------------------------------|------|
|           | Financial   |          |          | I                  | Institutional |          |                                       |      |
| <u>RT</u> | <u>S nª</u> | Charges  | SD       | Ranges             | Costs         | SD       | Ranges                                | LOS  |
| 0         | 27          | \$10,572 | \$29.313 | \$1,272 -\$154,438 | \$9,110       | \$19,270 | \$2.388 -\$103.461                    | 2.4  |
| 2         | 1           | 5,266    | 0        | 5,266 - 5,266      | 5,528         | 0        | 5,528 - 5,528                         | 1.0  |
| 3         | 6           | 38,098   | 64,557   | 2,807 - 168,086    | 28,452        | 43,961   | 4,628 - 117,148                       | 10.7 |
| 4         | 14          | 57,914   | 75,683   | 8,036 - 248,685    | 37,463        | 45,468   | 7,127 - 151,255                       | 13.7 |
| 5         | 15          | 42,059   | 32,733   | 7,313 - 121,784    | 28,509        | 19,773   | 6,421 - 75,459                        | 9.2  |
| 6         | 21          | 35,796   | 22,229   | 6,722 - 91,250     | 24,937        | 14,288   | 6,372 - 57,613                        | 8.0  |
| 7         | 10          | 24,044   | 21,147   | 7,082 - 79,714     | 17,039        | 14,132   | 6,040 - 55,258                        | 6.4  |
| 8         | 8           | 41,558   | 42,095   | 7,610 - 117,058    | 28,372        | 25,748   | 8,128 - 72,540                        | 12.0 |
| 9         | 15          | 37,364   | 25,840   | 10,512 - 101,612   | 25,687        | 16,344   | 8,745 - 68,452                        | 8.3  |
| 10        | 25          | 31,384   | 19,524   | 10,926 - 84,307    | 21,775        | 12,445   | 8,789 - 56,742                        | 7.4  |
| 11        | 54          | 30,719   | 26,707   | 5,169 - 122,716    | 21,932        | 17,343   | 5,609 - 81,692                        | 8.7  |
| 12        | 168         | 20,798   | 35,472   | 2,752 - 416,036    | 15,297        | 21,103   | 3,281 - 241,843                       | 5.8  |

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#### Research Ouestion 5

What is the relationship between financial charges and institutional costs and severity of injury as assessed by the Injury Severity Score (ISS)?

The ISS is a research tool for which scores increase exponentially with greater injury severity and number of injuries. This score is calculated after all the injuries are known. A scatter plot was used to determine nonlinearity of the data, and one-way ANOVA provided significant F levels, with p values of 0.0001 and 0.0001, respectively, for financial charges and costs based on the ISS. Summaries of ANOVAs for the ISS are shown in Tables 16 and 17. Most of the patients had ISS scores of 4 to 34. See Table 18 and Figures 10 and 11 for the frequencies, mean financial charges, mean institutional costs, standard deviations, ranges, and mean LOS for each ISS score. Since more ISS scores are possible, each category contains fewer patients. Unlike the GCS and the RTS, in which *low* scores equate to more severe injuries, ISS numbers *increase* for patients who experience more severe injuries. Patients with injuries so severe they are unlikely to survive are given a score of 75. The highest number of patients (43) had an initial ISS of 75, with mean financial charges of \$10,537. They represent 53% of the 81 patients in the study who died.

ISS scores of 35 and 42 had the highest mean financial charges, The six patients with an ISS of 35 included the patient who had the highest institutional cost (\$416,036) of all the patients. These six patients had a mean LOS of 19.2 days. The ISS of 42, charged \$168,086, represented only one patient, and that patient's LOS was 53 days.

| Summary ANOVA: | Patients' Mean | Financial Charges | <u>s by Injury Severity Sco</u> | re (ISS) |
|----------------|----------------|-------------------|---------------------------------|----------|
|                |                |                   |                                 |          |
|                |                |                   |                                 |          |

| Source | df  | SS        | MS        | F    | p        |
|--------|-----|-----------|-----------|------|----------|
| ISS    | 46  | 1.580E+11 | 3.434E+09 | 3.49 | < 0.0001 |
| Error  | 303 | 2.980E+11 | 983460270 |      |          |
| Total  | 349 | 4.560E+11 |           |      |          |

## Table 17

# Summary ANOVA: Patients' Institutional Costs by Injury Severity Score (ISS)

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| Source | df  | SS        | MS        | F    | p        |
|--------|-----|-----------|-----------|------|----------|
| ISS    | 46  | 6.146E+10 | 1.336E+09 | 3.69 | < 0.0001 |
| Error  | 303 | 1.098E+11 | 362330110 |      |          |
| Total  | 349 | 1.712E+1  |           |      |          |
|        |     |           |           |      |          |

| Patients' Mean Financial Charges and Institutional Costs (SD, Ranges, and Length of Stav [LC | <u> (S]) by</u> |
|--|-----------------|
| Injury Severity Score (ISS)  |                 |

|            | _         | Mean      |         |                           | Mean         |         |                    |            |
|------------|-----------|-----------|---------|---------------------------|--------------|---------|--------------------|------------|
|            |           | Financial |         |                           | Institutiona | ıl      | Mean               |            |
| <u>ISS</u> | <b>n*</b> | Charges   | SD      | Ranges                    | Costs        | SD      | Ranges I           | <u>.0s</u> |
| 0          | 4         | \$5,614   | \$5,308 | \$2,097 <b>-</b> \$13,473 | \$6,074      | \$4,333 | \$3,281 - \$12,526 | 1.0        |
| 1          | 4         | 10,877    | 6,966   | 3,758 - 19,654            | 10,095       | 3,735   | 5,788 - 13,315     | 3.0        |
| 2          | 2         | 9,001     | 2,041   | 7,558 - 10,445            | 8,155        | 803     | 7,587 - 8,723      | 1.0        |
| 4          | 19        | 10,172    | 8,523   | 3,049 - 42,948            | 8,534        | 5,090   | 3,873 - 27,882     | 2.2        |
| 5          | 10        | 9,707     | 3,950   | 4,693 - 15,373            | 8,564        | 2,279   | 5,512 - 12,163     | 2.4        |
| 6          | 3         | 14,922    | 3,050   | 11,571 - 17,537           | 11,586       | 1,597   | 9,962 - 13,154     | 3.7        |
| 8          | 7         | 16,339    | 11,366  | 5,400 - 37,248            | 13,114       | 7,451   | 5,138 - 27,962     | 4.9        |
| 9          | 18        | 17,340    | 11,236  | 3,158 - 51,826            | 12,894       | 7,276   | 3,730 - 34,333     | 5.5        |
| 10         | 15        | 14,148    | 8,535   | 5,169 - 32,457            | 11,156       | 5,785   | 5,609 - 24,205     | 4.4        |
| 11         | 6         | 16,385    | 10,761  | 4,135 - 33,572            | 12,120       | 6,987   | 4,226 - 24,131     | 5.0        |
| 12         | 7         | 17,600    | 7,513   | 7,868 - 25,516            | 13,083       | 4,963   | 6,871 - 18,742     | 5.0        |
| 13         | 8         | 20.856    | 11,702  | 4,938 - 40,573            | 15,799       | 7,520   | 6,145 - 28,195     | 6.1        |
| 14         | 17        | 13,414    | 8,392   | 5,040 - 38,101            | 10,061       | 5,161   | 3,292 - 24,120     | 3.3        |
| 15         | I         | 5,205     | 0       | 5,205 - 5,205             | 6,078        | 0       | 6,078 - 6,078      | 1.0        |
| 16         | 9         | 44,047    | 78,534  | 4,025 -248,685            | 29,446       | 47,056  | 3,860 -151,255     | 11.7       |
| 17         | 11        | 21,370    | 10,053  | 10,413 - 42,248           | 15,502       | 7,302   | 7,929 - 31,020     | 8.5        |
| 18         | 4         | 26,911    | 14,830  | 17,610 - 48,778           | 20,836       | 7,916   | 13,236 - 30,870    | 8.5        |
| 19         | 10        | 22,936    | 10,986  | 8,044 - 41,194            | 16,473       | 6,944   | 7,904 - 30,142     | 6.8        |
| 20         | 9         | 24,807    | 15,002  | 9,814 - 50,185            | 18,152       | 10,352  | 8,534 - 34,884     | 8.0        |
| 21         | 4         | 28,266    | 22,951  | 12,102 - 62,268           | 19,503       | 13,776  | 10,199 - 39,821    | 8.5        |
| 22         | 15        | 26,638    | 12,945  | 12,064 - 53,356           | 18,868       | 8,979   | 9,001 - 38,224     | 8.5        |

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| 24 | 14 | 25,451  | 14,619  | 8,813 - 48,998   | 18,057  | <b>9.06</b> 1 | 6,097 - 32,330   | 7.5  |
|----|----|---------|---------|------------------|---------|---------------|------------------|------|
| 25 | 12 | 21,295  | 13,690  | 2,904 - 54,333   | 16,478  | 9,241         | 3,147 - 37,171   | 5.3  |
| 26 | 6  | 25,861  | 18,762  | 12,288 - 60,905  | 18,271  | 12,697        | 8,821 - 41,824   | 7.0  |
| 27 | 2  | 31,691  | 583     | 31,279 - 32,103  | 21,615  | 881           | 20,992 - 22.238  | 8.5  |
| 29 | 17 | 41,732  | 32,863  | 8,931 -122,716   | 29,410  | 21,614        | 7,580 - 81,692   | 11.9 |
| 30 | 5  | 58,414  | 28,733  | 13,815 - 83,844  | 36,777  | 16,335        | 11,782 - 50,728  | 15.0 |
| 33 | 5  | 42,023  | 57,534  | 14,419 -144,917  | 30,414  | 40,196        | 11,406 -102,295  | 14.9 |
| 34 | 11 | 50,154  | 29,658  | 8,036 -110,967   | 33,228  | 18,855        | 7,127 - 72,269   | 10.8 |
| 35 | 6  | 113,385 | 151,704 | 10,926 -416,036  | 69,341  | 86,804        | 10,489 -241,843  | 19.2 |
| 36 | 7  | 32,018  | 26,437  | 6,882 - 79,714   | 22,815  | 18,648        | 4,246 - 55,258   | 11.3 |
| 38 | 6  | 42,236  | 14,321  | 23,581 - 54,708  | 31,193  | 10,193        | 17,963 - 41,649  | 10.4 |
| 40 | 1  | 24,633  | 0       | 24,633 - 24,633  | 16,817  | 0             | 16,817 - 16,817  | 7.0  |
| 41 | 2  | 45,293  | 5,462   | 41,431 - 49,156  | 31,482  | 3,477         | 29,024 - 33,941  | 8.5  |
| 42 | 1  | 168,086 | 0       | 168,086 -168,086 | 117,148 | 0             | 117,148 -117,148 | 53.0 |
| 43 | 6  | 38,007  | 33,166  | 11,501 - 90,729  | 25,575  | 19,500        | 9,516 - 55,961   | 7.3  |
| 45 | 3  | 38,155  | 19.595  | 15,984 - 53,148  | 26,227  | 12,113        | 12,242 - 33,340  | 8.7  |
| 47 | l  | 97,869  | 0       | 97,869 - 97,869  | 58,486  | 0             | 58,486 - 58,486  | 24.0 |
| 48 | 4  | 82,122  | 80,420  | 16,761 -194,735  | 53,389  | 48,823        | 13,474 -121,057  | 13.0 |
| 50 | 2  | 34,921  | 12,504  | 29,079 - 43,763  | 25,424  | 6,155         | 21,072 - 29,776  | 8.0  |
| 51 | 1  | 9,653   | 0       | 9,653 - 9,653    | 8,462   | 0             | 8,462 - 8,462    | 1.0  |
| 54 | 1  | 31,728  | 0       | 31,728 - 31,728  | 19,927  | 0             | 19,927 - 19,927  | 1.0  |
| 57 | 3  | 64,403  | 51,372  | 22,687 -121,784  | 42,707  | 30,275        | 15,744 - 75,459  | 16.0 |
| 59 | 3  | 76,565  | 71,537  | 13,767 -154,438  | 52,335  | 47,014        | 10,962 -103,461  | 18.7 |
| 64 | 1  | 28,728  | 0       | 27,496 -121,312  | 22,649  | 0             | 22,649 - 22,649  | 1.0  |
| 66 | 4  | 70,128  | 45,590  | 1,272 -117,059   | 45,713  | 26,890        | 19,775 - 73,050  | 16.0 |
| 75 | 43 | 10,537  | 18,522  | 2,863 -101,612   | 8,773   | 11,293        | 2,388 - 72,540   | 2.2  |
|    |    |         |         |                  |         |               |                  |      |

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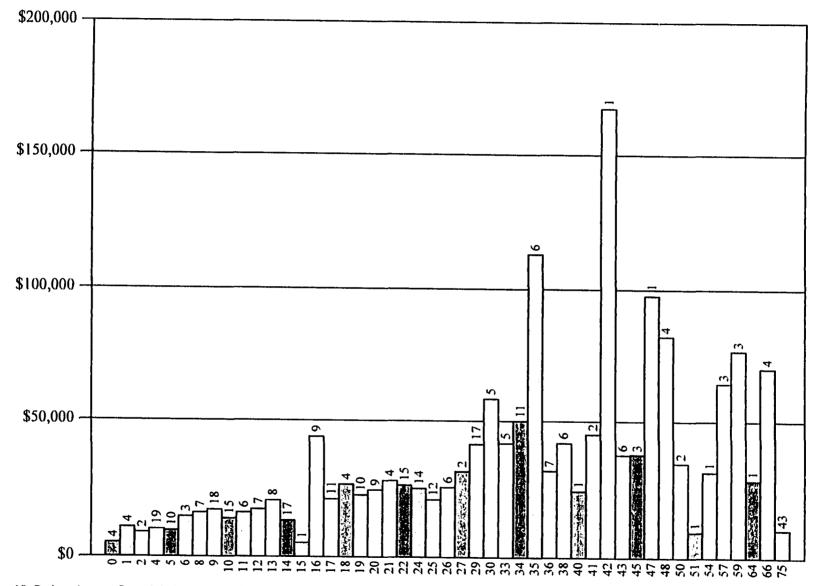


Figure 10, Patients' mean financial charges by Injury Severity Score (ISS).

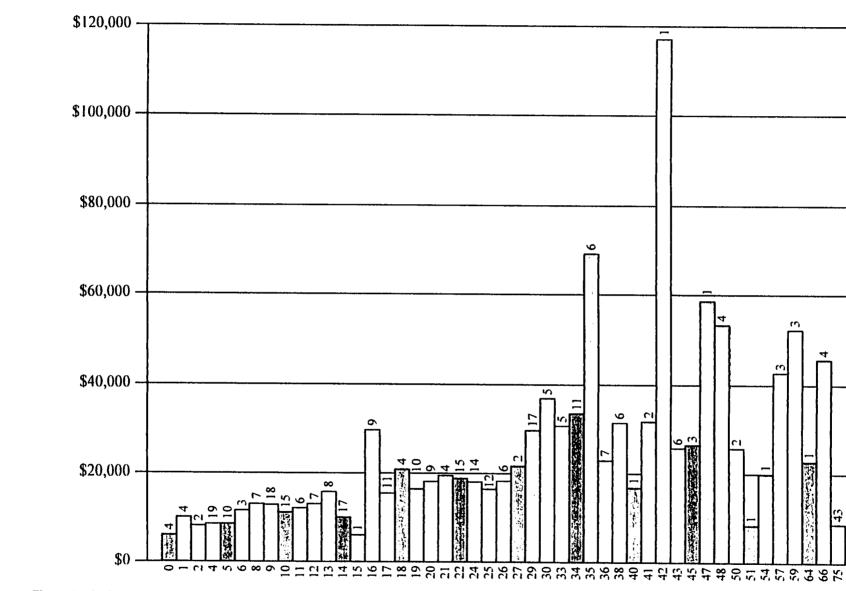


Figure 11, Patients' mean institutional costs by Injury Severity Score (ISS).

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To provide more meaning to the ISS scores, the data have been collapsed by conventional use. (See Tables 19 and 20 for ANOVA summaries.) One-way ANOVAs provided significant F tests with p values of <0 .001 for each. Table 21 provides collapsed frequencies, means, standard deviations, ranges, and LOS.

ISS Scores less than 15 are considered indicative of minor injuries; scores of 15 to 50 imply moderate injuries, and scores greater than 50 denote severe injuries. One hundred twenty-one patients (33%) had ISS scores of 15 or lower, with 4 patients who died. That group had a mean LOS of 3.9 days with mean financial charges of \$13,948. One hundred seventy-four patients (47%) comprised the moderately injured group (ISS 15-50). As Figures 12 and 13 show, validated by t-test (p = <0.0001), patients with moderate injuries had significantly higher financial charges of \$37,835 and a mean LOS of 9.9 days. Three of the moderately injured group died in the ED, but 22 died during acute care.

Fifty-six patients (15%) had the highest and most severe injury designation (ISS 51-75). The mean financial charge for this group was \$21,905, with a mean LOS of 4.8 days. These severely injured patients had statistically significantly higher charges, costs, and LOS than those with mild injuries. Eighty-eight percent of them died, twenty-one in the ED in the first day, utilizing fewer health care resources, and twenty-eight during acute care, utilizing more resources.

Table 19

#### Summary ANOVA: Patients' Financial Charges by Collapsed Injury Severity Score (ISS)

| Source | df  | SS        | MS        | F     | p      |
|--------|-----|-----------|-----------|-------|--------|
| ISS    | 2   | 4.249E+10 | 2.125E+10 | 17.87 | <0.001 |
| Error  | 348 | 4.138E+11 | 1.189E+09 |       |        |
| Total  | 350 | 4.563E+11 |           |       |        |

| ISS 2 1.696E+10 8.480E+09 19.10 <0.001 |
|--|
| Error 348 1.545E+11 443893174          |
| Total 350 1.714E+11                    |

In summary, as with the GCS, patients with the best and the worst ISS scores had statistically significantly lower financial charges and institutional costs than those with moderate injuries. Again, more of those with severe injuries died in the ED and mildly injured patients also had shorter LOS, requiring fewer health care resources. However, unlike the GCS, severely injured patients had significantly higher financial charges and institutional costs than the mildly injured patients.

## Table 21

Patients' Mean Financial Charges and Mean Institutional Costs (SD, Ranges, and Length of Stav [LOS]) by Collapsed Injury Severity Score (ISS)

|              | Mean             |   |   | Mean   |   |  |   |
|--------------|------------------|---|---|--|---|--|---|
|              | Financial        |   |   | Institutiona   | 1   | N  | Mean  |
| _ <u>n</u> * | Charges          | SD  | Ranges  | Costs  | SD  | Ranges LO  | <u>DS</u>   |
| 121          | <b>\$</b> 13,948 | \$9,244   | \$2,097 - \$51,826  | \$10,964   | \$5,901   | \$3,281 - \$34,333   | 3.9   |
| 174          | 37,835           | 44,193  | 2,904 - 416,036   | 26,057   | 26,829  | 3,147 - 241,843  | 9.9   |
| 56           | 21,905           | 34,559  | 1,272 - 154,438   | 16,005   | 21,647  | 2,388 - 103,461  | 4.8   |
|              | 121<br>174       | Financial<br><u>n<sup>a</sup></u> Charges<br>121 \$13,948<br>174 37,835 | Financial<br><u>n<sup>a</sup> Charges SD</u><br>121 \$13,948 \$9,244<br>174 37,835 44,193 | Financial     n <sup>a</sup> Charges     SD     Ranges       121     \$13,948     \$9,244     \$2,097 - \$51,826       174     37,835     44,193     2,904 - 416,036 | Financial     Institutiona       n <sup>a</sup> Charges     SD     Ranges     Costs       121     \$13,948     \$9,244     \$2,097 - \$51,826     \$10,964       174     37,835     44,193     2,904 - 416,036     26,057 | Financial     Institutional       n <sup>a</sup> Charges     SD     Ranges     Costs     SD       121     \$13,948     \$9,244     \$2,097 - \$51,826     \$10,964     \$5,901       174     37,835     44,193     2,904 - 416,036     26,057     26,829 | Financial     Institutional     M       n <sup>a</sup> Charges     SD     Ranges     Costs     SD     Ranges     LC       121     \$13,948     \$9,244     \$2,097 - \$51,826     \$10,964     \$5,901     \$3,281 - \$34,333       174     37,835     44,193     2,904 - 416,036     26,057     26,829     3,147 - 241,843 |

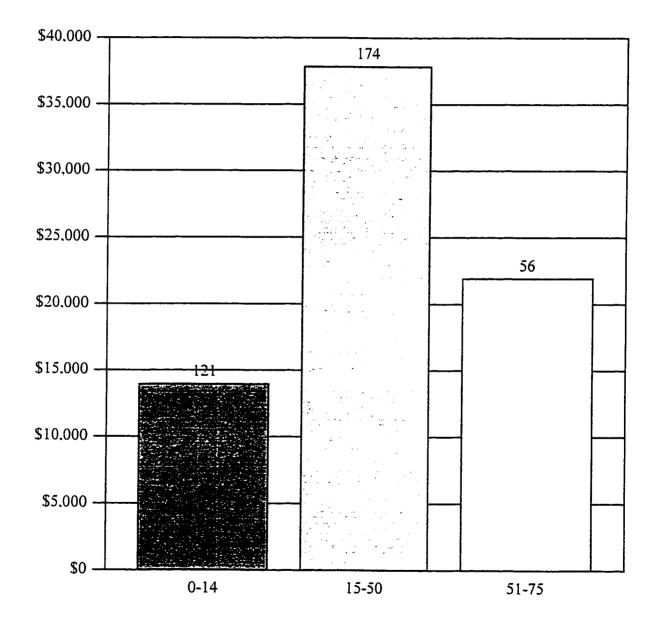


Figure 12. Patients' mean financial charges by collapsed Injury Severity Score (ISS).

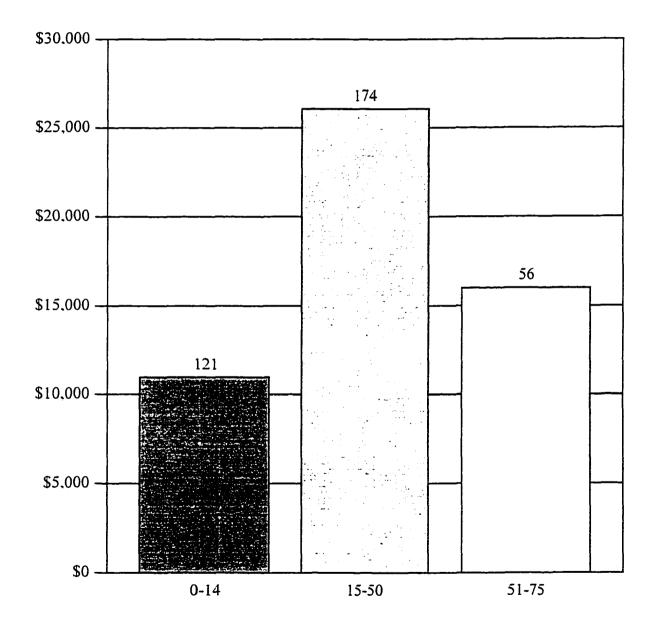


Figure 13. Patients' mean institutional costs by collapsed Injury Severity Score (ISS).

#### Research Ouestion 6.

Who pays the financial charges of major trauma patients' care?

There were seven categories of payers for financial charges: commercial insurance, Medicare/Medicaid, Workmen's Compensation, charity, self-pay, active duty military, and crime victim compensation. Total financial charges for the three-hundred seventy major trauma patients were \$9,945,973. One way ANOVA showed no statistically significant difference in financial charges paid (p = .441) by different payer groups. See Table 22 for the frequencies, means and percentages and Figures 14 and 15 for financial charges or institutional costs among payers. In summary, commercial and governmental insurance covered most major trauma patients, with no statistical differences in charges and institutional costs among payer groups. This is in contrast to other studies where the majority of patients had no insurance.

#### Table 22

### Payers, Percentages Paid by Each Payer, Mean Financial Charges, and Mean Institutional Costs

|                      |     | % paid by  | Mean     | Mean                |
|----------------------|-----|------------|----------|---------------------|
| Payer                | n   | each payer | Charges  | Institutional Costs |
| Commercial           | 261 | 71%        | \$27,929 | \$19,820            |
| Medicare/Medicaid    | 35  | 09%        | 32,784   | 23,196              |
| Workmen's Comp*      | 38  | 10%        | 26,086   | 18,552              |
| Charity              | 12  | 03%        | 14,570   | 11,137              |
| Self Pay             | 9   | 02%        | 13,065   | 10,845              |
| Active Duty Military | 4   | 01%        | 8,523    | 6,878               |
| Crime Victim Comp*   | 11  | 03%        | 17,396   | 12,849              |

\* Compensation

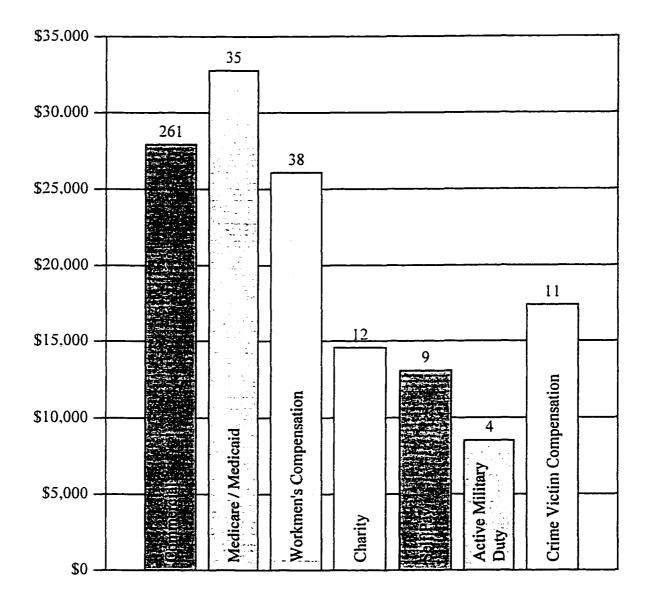


Figure 14. Mean financial charges by payers.

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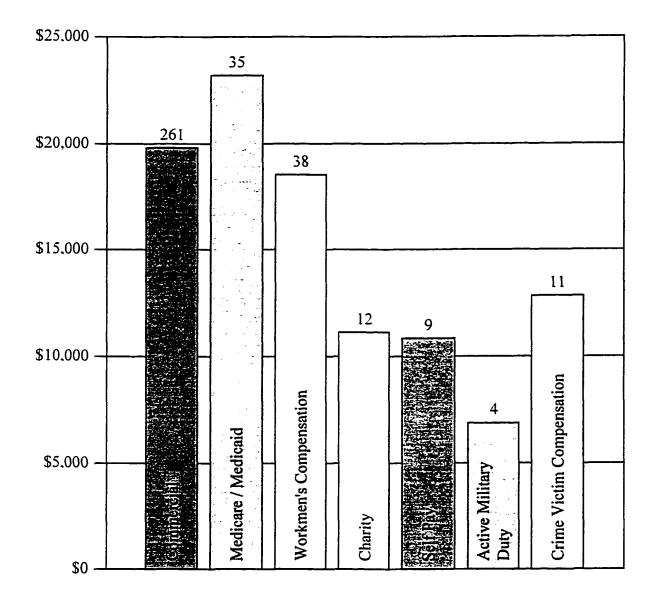


Figure 15. Mean institutional costs by payers

#### Research Question 7

What is the relationship between financial charges and institutional costs and discharge outcome for surviving major trauma patients as measured by Glasgow Outcome Score (GOS)?

The GOS determines the physical outcome for trauma patients at discharge. Outcomes include death, persistent vegetative state (PVS), severe disability, moderate disability, and good recovery. Data from the GOS scores, the financial charges, and institutional costs were analyzed with one-way ANOVAs, which produced significant F tests and p values of 0.0001 and 0.0001, respectively. The summaries of ANOVA for the GOS are shown in Tables 23 and 24 with means, standard deviations, ranges, and LOS in Table 25. Differences in mean financial charges and costs are shown graphically in Figures 16 and 17. Patients who died are described at length in sections related to questions one and two.

Financial charges for all five categories differ statistically from each other except for GOS 1 and GOS 5. (See Tables 31 and 32 for the frequencies, means, standard deviations, and LOS for each of the GOS scores.) Clinically, the patients differed significantly in ability to function physically. Aside from those who died, those eventually categorized as PVS first required numerous health care resources to survive and overcome complications, before transfer to an extended care facility. The three patients from this study who were designated PVS had mean financial charges of \$79,185 and a mean LOS of 24.7 days.

Table 23

#### Summary ANOVA: Patients' Financial Charges by Glasgow Outcome Score (GOS)

| Source | df  | SS        | MS        | F     | p      |  |
|--------|-----|-----------|-----------|-------|--------|--|
| GOS    | 4   | 9.713E+10 | 2.428E+10 | 24.00 | 0.0001 |  |
| Error  | 346 | 3.501E+11 | 1.012E+09 |       |        |  |
| Total  | 350 | 4.472E+11 |           |       |        |  |

| Source | df  | ŞS        | MS        | F     |        |
|--------|-----|-----------|-----------|-------|--------|
| GOS    | 4   | 3.825E+10 | 9.563E+09 | 25.43 | 0.0001 |
| Error  | 346 | 1.301E+11 | 376106211 |       |        |
| Total  | 350 |           | 1.684E+11 |       |        |

A GOS of 5 represented patients with good recovery, that is, with restoration of capabilities to return to their pre-injury lifestyles. They could return to previous social, professional, or job interactions, even with minor physical or neurological deficits. The highest number of patients (131) had an initial GOS of 5 and mean financial charges of \$14,391. Their mean LOS was 4.2 days, compared to those with a GOS of 4 who had 9.2 days and those with a GOS of 3 whose a mean LOS was 13.7 days.

In summary, unlike the earlier trauma scoring systems, there is a linear relationship between GOS scores and financial charges/institutional costs, after categorizing those who died with a score of 1. Those with poorer outcomes had significantly higher LOS, financial charges, and institutional costs.

## Patients' Mean Financial Charges and Mean Institutional Costs (SD, Ranges, and Length of Stay [LOS])

|     | Mean      |          |               |                    | Mean     |          |                    |      |
|-----|-----------|----------|---------------|--------------------|----------|----------|--------------------|------|
|     | Financial |          | Institutional |                    |          |          |                    |      |
| GOS | nª.       | Charges  | SD            | Ranges             | Costs    | SD       | Ranges             | LOS  |
| I   | 81        | \$15,669 | \$17,440      | \$1,272 -\$117,059 | \$12,129 | \$10,944 | \$2,388 - \$72,540 | 2.7  |
| 2   | 3         | 79,185   | 18,485        | 60.905 - 97,869    | 50,114   | 8,331    | 41.824 - 58.486    | 24.7 |
| 3   | 83        | 53,242   | 58,446        | 8,069 - 416,036    | 35,705   | 35,209   | 7,298 - 214,843    | 13.7 |
| 4   | 53        | 30,728   | 20,614        | 7,187 - 122,716    | 21,975   | 13,268   | 6,489 - 81,692     | 9.2  |
| 5   | 131       | 14,391   | 13,268        | 2,863 - 121,312    | 11,190   | 8,595    | 3,281 - 72,269     | 4.2  |

## by Glasgow Outcome Score (GOS)

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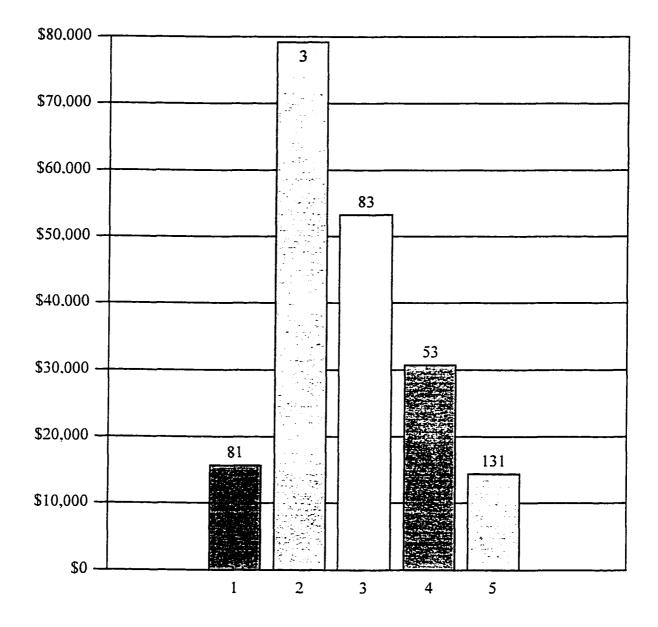


Figure 16. Patients' mean financial charges by Glasgow Outcome Score (GOS).

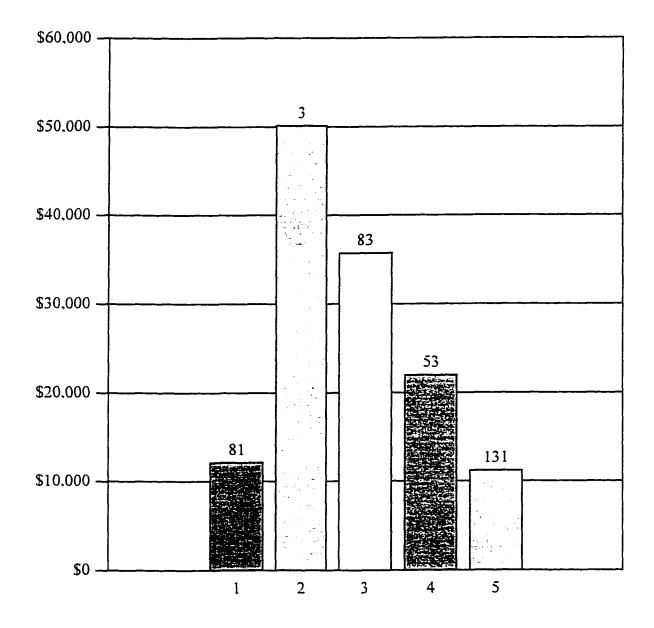


Figure 17. Patients' mean institutional costs by Glasgow Outcome Score (GOS).

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#### Research Ouestion 8

What are the differences in physical function costs, as measured by Functional Independence Measure (FIM), for patients at 6 months to 1 year, at 2 years, at 3 to 4 years, and at 5 years post-trauma?

After data collection, results from the 20 patients who were evaluated were placed in four groups to increase the power of statistical analysis. Group 1 represents those 6 months to 1 year post-trauma. Group 2 covers those 2 years post-trauma. Group 3 reflects those 3 to 4 years post-trauma. Group 4 contains patients five years post-trauma (see Table 26).

All twenty of the patients who were interviewed received all the points that dealt with physical function for the FIM (see Appendix I). That is, patients who perform each of the tasks, even part of the time, receive all of the points (S. Macnamara PhD., personal communication, November, 1997). Therefore, there were no statistically significant differences among the four groups for physical function.

However, these patients had marked clinical differences. After learning to walk again, one patient at 3 to 4 years post-trauma now walks slowly, with occasional pain and numbness. Another patient at 3 to 4 years post-trauma and one at 2 years post-trauma can walk for short distances, but both use wheel chairs frequently to conserve energy. Neither of them can go up or down stairs. One patient at 5 years post-trauma and one patient in the 6 months to 1 year post-trauma period get dizzy when leaning over and must stand still for a period of time before continuing previous activities.

Five years post-trauma, one patient returned to work, full time, a week before he was interviewed. Two patients at 3 to 4 years post-trauma and one at 2 years post-trauma work part time. One patient from the 3 to 4 years post-trauma group changed occupations and also receives disability insurance. Clearly, despite the absence of statistical differences, clinical differences were pronounced for individual patients in the four groups. However, no distinct differences in physical function distinguished groups whose health improved over time.

#### Functional Independence Measure (FIM) Groups

| Year of   |          |                                     |
|-----------|----------|-------------------------------------|
| Injury    | <u>n</u> | Groups                              |
| 1995-96   | 7        | 6 months to 1 year-year post-trauma |
| 1994      | 3        | 2 years post-trauma                 |
| 1992-1993 | 5        | 3 to 4 years post-trauma            |
| 1991      | 5        | 5 years post-trauma                 |
|           |          |                                     |

#### Research Question 9

What are the differences in psychosocial costs, as measured by the HDL-B, for surviving patients at 6 months to 1 year, at 2 years, at 3 to 4 years, and at 5 years post-trauma?

Data collected for the 20 patients who were evaluated were placed in of four groups to increase the power of statistical analysis. Group 1 represents those six-months-to-one year post-trauma, group 2 two years post-trauma, group 3 three-to-four years post-trauma, and group 4 five years post-trauma.

The HDL-B is a research tool for "sociodemographic data, with sets of indices that tap health-related and social functioning, chronic and acute life stressors, social resources, and help-seeking" (Moos et al., 1990 p. 7). The demographic data section covers age, ethnicity, religion, education, marital status, employment history, personal income, and family income. Other indices include health-related functioning, social functioning and resources, family functioning and home environment, children's health and functioning, indices of life change events, indices of help-seeking, and indices of family composite.

Data from the groups of scores for the HDL-B were analyzed with one-way ANOVA. Table 27 shows the ANOVA results for each of the indices for the HDL-B. There were no significant differences between any of the groups, except for family tasks and partner tasks, with their respective p = .0106 and p = .0457. T-tests revealed that patients at 5 years post-trauma shared in more family tasks than did patients from the 2 year and 6 months to 1 year groups (p = .0436 and p = .0012, respectively.) Conversely,

according to t-tests, patients at 5 years post-trauma reported fewer tasks performed by others than reported by patients 3 to 4 years post-trauma and 6 months to 1 year post-trauma (p = .0437 and p = .0063, respectively.)

When examining the HDL-B data for patients, two additional questions arise: (a) Are there differences between those surviving patients who responded to the HDL-B and those who could not be located? (b) Are there differences between the HDL-B respondents in this study and members of a control population examined by the HDL-B's developers? The first of these questions is addressed here. The second question is answered after question 10, which refers to family HDL-B responses.

|                                | <u></u> | . <u> </u> |       |
|--------------------------------|---------|------------|-------|
| Indices                        | df      | F          | p     |
| Age                            | 3       | 0.22       | .8808 |
| Gender                         | 3       | 1.43       | .2472 |
| Years working                  | 3       | 0.35       | .7924 |
| Earnings                       | 3       | 1.28       | .2950 |
| Family earnings                | 3       | 0.50       | .6842 |
| Self concept                   | 3       | 0.32       | .8128 |
| Global Depression              | 3       | 1.77       | .1659 |
| Depressive Features            | 3       | 2.34       | .0920 |
| Endogenous Depression          | 3       | 2.39       | .0891 |
| Depressive Mood                | 3       | 1.46       | .2382 |
| Family Tasks                   | 3       | 4.21       | .0106 |
| Partner Tasks                  | 3       | 2.90       | .0457 |
| Contact with Friends           | 3       | .083       | .4851 |
| Social Contacts                | 3       | 1.95       | .1356 |
| Close Relationships            | 3       | 0.60       | .6205 |
| Significant relationships      | 3       | 0.11       | .9558 |
| Family social activities       | 3       | 1.85       | .1517 |
| Tasks performed by the patient | 3       | 0.17       | .9142 |
| Home environment               | 3       | 1.31       | .2822 |
|                                |         |            |       |

<sup>a</sup> Group 1 = patients at 6 months to 1 year post-trauma; Group 2 = patients at 2 years; Group 3 = patients at 3 to 4 years; Group 4 = patients at 5 years post-trauma.

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Respondents versus nonrespondents. Table 28 shows known differences between survivors who responded to the HDL-B and those who did not. The ages of the respondents differed significantly (p = 0.0217) from those of nonrespondents. As a group, respondents were 30.64 years old and nonrespondents were 34.70 years old. Statistically significant differences also distinguished the financial charges (p = .0052), institutional costs (p = .0121), who paid them (p = .0015), and the RTS (p = .0399) for respondents versus nonrespondents. Those who responded had mean financial charges of \$27,554,whereas those who did not respond had a mean financial charge of \$43,527. Commercial insurance paid for 41 out of 49 (84%) of the respondents, workmen's compensation paid for 7 (14%), and charity paid for 1 (2%), while nonrespondents' payers looked much different: commercial insurance paid for 67.6%, Medicare/Medicaid paid for 12.7%, Workmen's Compensation paid for 8.5%, charity paid for 3.9%, self-pay covered 3.1%, active duty military paid 1.2%, and crime victim compensation paid for 3.1% of the nonrespondents (see Table 29.) Although there was a statistically significant difference in RTS scores (10.78 for respondents and 10.02 for nonrespondents), such small differences are not clinically significant. In summary, respondents were younger, had lower financial charges/institutional costs, and more traditional sources of payment.

#### Table 28

| Indices | Respondents | Nonrespondents | df | F    | p     |
|---------|-------------|----------------|----|------|-------|
| Age     | 30.64       | 34.70          | 1  | 5.32 | .0217 |
| RTS     | 10.78       | 10.02          | 1  | 4.26 | .0399 |
| Charges | \$27,554    | \$43,527       | 1  | 6.96 | .0088 |
| Cost    | \$19,689    | \$29,067       | 1  | 6.38 | .0121 |
| Payers  |             |                | 1  | 4.30 | .0390 |

Summary ANOVA: Characteristics Respondents versus Nonrespondents

### Payers for Respondents versus Nonrespondents

| Pavers                    | Respondents | Nonrespondents |
|---------------------------|-------------|----------------|
| Commercial Insurance      | 84 %        | 69%            |
| Medicare/Medicaid         | 0           | 11%            |
| Workmen's Compensation    | 14%         | 10%            |
| Charity                   | 2%          | 3%             |
| Self pay                  | 0           | 3%             |
| Active Duty Military      | 0           | 1%             |
| Crime Victim Compensation | 0           | 3%             |
|                           |             |                |

#### Research Ouestion 10

What are the differences in psychosocial costs, as measured by the HDL-B, for families of surviving patients at 6 months to 1 year post-trauma, at 2 years post-trauma, at 3 to 4 years post-trauma, and at five years post-trauma?

Data from the HDL-B indices for family members of major trauma patients were collapsed into four groups to increase the power of statistical analysis. Group 1 represents those 6 months to 1 year post-trauma, group 2 two years post-trauma, group 3 three to four years post-trauma, and group 4 five years post-trauma.

Data from the groups of scores for the family members' HDL-B were analyzed using one-way ANOVA, which determined F tests and corresponding p values. Table 30 shows the ANOVA results for each of the indices for the HDL-B. No statistically significant differences marked any of the groups, except for *Depressive Mood* (p = .0070), Negative Events in the last 12 months (p = .0167), Single Events in the

last 3 months (p = .0111), Single Events in the last 6 months (p = .0156), and Single Events in the last 12 months (p = .0433). Additional t-tests were run to determine which groups were different.

Family members who were 3 to 4 years post-trauma had more *Depressive Feelings* (Feeling depressed; feeling guilty, worthless, or down on yourself; thoughts about death or suicide: feeling negative or pessimistic; brooding about unpleasant things; feeling inadequate; and feeling sorry for yourself) than family members who were 5 years post-trauma (p = .0026) and more than family members who were 6 months to 1 year post-trauma (p = .0035).

At 5 years and 3 to 4 years post-trauma, family members had more *Negative Events* (lost something of sentimental value; death of a close friend; trouble with friends or neighbors; separation; divorce; trouble with in-laws; death of a spouse; death of immediate family member other than spouse; trouble with superiors at work; laid off or fired from a job, unemployed for a month or more; income decreased substantially; went deeply into debt; legal problems; assaulted or robbed) in the last 1-12 months than family members who are 2 years post-trauma (p = .0328 and p = .0393 respectively).

Family members at 5 years and 3 to 4 years post-trauma had fewer *Single Events* (moved to a new residence, had a greatly increased workload; your child left home; a child or other relative moved into household; alcohol or drug problem; your own serious illness or injury: serious illness or injury of family member) in the last 3 months (p = .0045 and p = .0029), in the last 6 months (p = .0040 and p = .0060), and in the last 12 months (p = .0116 and p = .0068) than family members at 2 years post-trauma.

Table 30

Summary ANOVA: Health and Daily Living Form B (HDL-B) Indices for Family Members by Time Posttrauma<sup>a</sup>

| Indices                     | df | F    | p     |
|-----------------------------|----|------|-------|
| Age                         | 3  | 0.22 | .7464 |
| Gender                      | 3  | 1.43 | .5187 |
| Years Working               | 3  | 0.35 | .7348 |
| Earnings                    | 3  | 1.28 | .7649 |
| Family Earnings             | 3  | 0.50 | .3584 |
| Self Concept                | 3  | 0.32 | .2266 |
| Global Depression           | 3  | 1.77 | .0988 |
| Depressive Features         | 3  | 2.34 | .1155 |
| Endogenous Depression       | 3  | 2.39 | .0547 |
| Depressive Mood             | 3  | 4.82 | .0070 |
| Family Tasks                | 3  | 4.21 | .0647 |
| Self Tasks                  | 3  | 2.52 | .0748 |
| Partner Tasks               | 3  | 2.90 | .1312 |
| Contact with Friends        | 3  | .083 | .3761 |
| Social Contacts             | 3  | 1.95 | .2624 |
| Close Relationships         | 3  | 0.60 | .3178 |
| Significant Relationships   | 3  | 0.11 | .6919 |
| Family Social Activities    | 3  | 1.85 | .5169 |
| Home Environment            | 3  | 1.31 | .2349 |
| Negative events 1-3 months  | 3  | 2.98 | .0505 |
| Negative events 1-6 months  | 3  | 1.30 | .2930 |
| Negative events 1-12 months | 3  | 3.93 | .0167 |
| Single events 1-3 months    | 3  | 4.35 | .0111 |
| Single events 1-6 months    | 3  | 4.01 | .0156 |
| Single events 1-12 months   | 3  | 3.04 | .0433 |

\* Group 1 = patients at 6 months to 1 year post-trauma; Group 2 = patients at 2 years; Group 3 = patients at 3 to 4 years; Group 4 = patients at 5 years.

<u>Trauma Patients and Families Compared to Community Members.</u> The HDL-B research tool also evaluates health, social means, help-seeking, and life stressors. The authors (Moos et al., 1990) administered the HDL-B to 267 pairs of randomly drawn community members as a control group.

When comparing patient to family perceptions for any of the HDL-B indices, there were no statistically significant differences, except for *Tasks Performed by Partner* (p = .033). However, when comparing patients and families to members of the community (see Table 31), differences became apparent. Surprisingly, in the *Self-Confidence and Symptom* indices, patients and families rated better for self-confidence than did community members. For medical conditions, global depression, depressive mood and ideation, endogenous depression, and depressive features, patients and families scored much higher (meaning they experienced more problems) than community members. Patients reported slightly fewer physical symptoms.

In the Substance Use and Problems section, patients and families scored considerably below community members for Alcohol Use, Frequency, Quantity, and Smoking. However, for Medication Use, patients and families were higher than the community.

Under Social Function and Resources, patients and families scored slightly below community members for Social Activities with Friends and the Number of Social Network Contacts. They scored much higher for the Number of Close Relationships and slightly higher for the Quality of Significant Relationships.

Conversely, for Family Functioning, patients and families scored slightly more Family Social Activities than community members. Patients scored slightly higher than community members for Family Task Sharing, whereas family members scored much higher than either. For Tasks Performed by Self, patients scored much lower than either families or community members. Patients scored considerably higher in Tasks Performed by Partner than did families, and slightly higher than community members. Patients and community members reported similar numbers of family arguments, but families reported more. Patients and families reported much more Negative Home Environment than did community members.

# Table 31

| Health and Daily Living (HD | L-B) Indices comparisons | s for patients, families, and community |
|-----------------------------|--------------------------|---|

| _                                       |               |       |       |                  |       |       |                   |       |       |  |
|---|---------------|-------|-------|------------------|-------|-------|-------------------|-------|-------|--|
| Self-confidence &<br>Symptoms           | pt*           | sd    | alpha | fam <sup>b</sup> | sd    | alpha | comm <sup>c</sup> | sd    | alpha |  |
| Self-Confidence                         | 20.36         | 5.03  | 0.81  | 19.14            | 6.1   | 0.85  | 14.63             | 4.31  | 0.77  |  |
| Physical Symptoms                       | 3             | 3.04  | 0.85  | 2.25             | 2.88  | 0.9   | 2.25              | 2.54  | 0.8   |  |
| Medical Conditions                      | 0.63          | 1.03  | *     | 0.56             | 1.00  | *     | 0.47              | 0.84  | *     |  |
| Global Depression                       | 38.06         | 16.07 | 0.95  | 36.08            | 15.88 | 0.95  | 19.21             | 11.79 | 0.92  |  |
| Depressive Mood &<br>Ideation           | 14.13         | 5.9   | 0.91  | 13.44            | 6.31  | 0.92  | 7.27              | 5.45  | 0.9   |  |
| Endogenous<br>Depression                | 17.15         | 7.29  | 0.89  | 15.06            | 7.44  | 0.87  | 7.97              | 5.28  | 0.8   |  |
| Depressive Features                     | 23.44         | 9.42  | 0.87  | 22.5             | 9.26  | 0.92  | 11.95             | 7.01  | 0.85  |  |
| Substance Use &<br>Problems             | pt            | sd    | alpha | fam              | sd    | alpha | comm              | sd    | alpha |  |
| Alcohol - quantity                      | 1.6           | 0.49  | *     | 1.64             | 0.49  | *     | 2.55              | 2.73  | *     |  |
| Alcohol - frequency                     | 0.2           | 0.40  | 0.92  | 0.11             | 0.24  | 0.92  | 0.76              | 1.72  | *     |  |
| Drinking problems                       | 0             | 0     | *     | 0                | 0     | *     | 0.11              | 0.56  | 0.74  |  |
| Smoking problems                        | 0             | 0     | *     | 0                | 0     | *     | 0.31              | 0.76  | 0.68  |  |
| Medication use                          | 2.3           | 1.42  | 0.07  | 2.8              | 3.6   | 0.48  | 2.01              | 1.52  | 0.53  |  |
| Social Function &<br>Resources          | pt            | sd    | alpha | fam              | sđ    | alpha | comm              | sd    | alpha |  |
| Social Activities with<br>Friends       | 4.5           | 3.92  | 0.84  | 4.0              | 3.23  | 0.76  | 5.38              | 2.79  | 0.73  |  |
| Social Network<br>Contacts              | 1 <b>7.29</b> | 18.45 | 0.72  | 14.72            | 10.79 | 0.42  | 17.95             | 14.71 | 0.48  |  |
| <b>Close Relationships</b>              | 17.19         | 21.45 | *     | 19.33            | 34.02 | *     | 6.77              | 5.85  | *     |  |
| Quality of Significant<br>Relationships | 18.40         | 5.07  | 0.4   | 18.17            | 5.16  | -0.54 | 16.77             | 3.5   | 0.72  |  |

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| Family Functioning            | pt    | sđ   | alpha | fam   | sd   | alpha | comm  | sd    | alpha |
|-------------------------------|-------|------|-------|-------|------|-------|-------|-------|-------|
| Family Social<br>Activities   | 4.88  | 3.13 | 0.8   | 5.06  | 3.63 | 0.69  | 4.82  | 2.84  | 0.75  |
| Family Task Sharing           | 27.83 | 0.20 | *     | 32.36 | 0.20 | *     | 26    | 18.31 | *     |
| Tasks Performed by Self       | 31.67 | 0.25 | *     | 40.14 | 0.23 | *     | 50.56 | 30.9  | •     |
| Tasks Performed by<br>Partner | 35.06 | 0.27 | *     | 23.53 | 0.19 | *     | 31.15 | 16.9  | *     |
| Family Arguments              | 2.55  | 2.39 | 0.65  | 2.91  | 3.12 | 0.81  | 2.58  | 2.59  | 0.75  |
| Negative Home<br>Environment  | 11.21 | 4.08 | 0.8   | 11.36 | 4.37 | 0.82  | 5.8   | 3.92  | 0.77  |
| Children's Health<br>Problems | pt    | sd   | alpha | fam   | sd   | alpha | comm  | sd    | alpha |
| Physical Health<br>Problems   | 0.542 | 0.99 | •     | I     | 1.55 | *     | 1.1   | 1.16  | *     |
| Psychological Health          | 0.25  | 0.7  | *     | 0.53  | 1.06 | *     | 0.9   | 1.07  | *     |
| Total Health<br>Problems      | 0.77  | 1.52 | •     | 1.5   | 2.43 | *     | 2     | 1.78  | *     |
| <b>Behavioral Problems</b>    | 0.16  | 0.56 | *     | 0.25  | 0.55 | *     | 0.39  | 0.72  | *     |
| Health-Risk<br>Behaviors      | 0.14  | 0.51 | *     | 0.19  | 0.58 | *     | 0.23  | 0.58  | *     |
| Life Change Events            |       |      |       |       |      |       |       |       |       |
| Negative Life<br>Events       | pt    | sd   | alpha | fam   | sd   | alpha | comm  | sd    | alpha |
| in past 3 months              | 0.33  | 0.66 | •     | 0.31  | 0.52 | *     | 0.64  | 1.01  | *     |
| in past 6 months              | 0.71  | 1.20 | *     | 0.64  | 0.93 | *     | 0.92  | 1.23  | *     |
| in past 12 months             | 1.58  | 1.98 | *     | 1.25  | 1.65 | *     | 1.35  | 1.5   | *     |
| Exit Events                   | pt    | sd   | alpha | fam   | sd   | alpha | comm  | sd    | alpha |
| in past 3 months              | 0.02  | 0.14 | *     | 0.06  | 0.23 | *     | 0.12  | 0.36  | *     |
| in past 6 months              | 0.10  | 0.31 | *     | 0.31  | 0.67 | *     | 0.19  | 0.47  | *     |
| in past 12 months             | 0.25  | 0.48 | *     | 0.39  | 0.80 | *     | 0.32  | 0.66  | *     |
| Positive Life Events          | pt    | sd   | alpha | fam   | sd   | alpha | comm  | sd    | alpha |
| in past 3 months              | 0.13  | 0.33 | *     | 0.14  | 0.35 | *     | 0.27  | 0.61  | *     |
| in past 6 months              | 0.31  | 0.66 | *     | 0.28  | 0.51 | *     | 0.47  | 0.76  | *     |
| in past 12 months             | 0.58  | 0.82 | *     | 0.53  | 0.94 | *     | 0.8   | 1     | *     |

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| Help-Seeking                                   | pt     | sd   | alpha | fam   | sd    | alpha | comm | sd   | alpha |
|--|--------|------|-------|-------|-------|-------|------|------|-------|
| Mental Professional<br>(last 12 months)        | 0.75   | 1.10 | *     | 0.64  | 1.05  | *     | 0.37 | 0.64 | *     |
| Mental Health<br>Professional (ever)           | 1.29   | 1.30 | *     | 1.08  | 1.21  | *     | 0.83 | 1    | *     |
| Non-Mental<br>Professional (last 12<br>months) | 0.38   | 0.64 | •     | 0.44  | 0.70  | *     | 0.33 | 0.65 | •     |
| Non-Mental<br>Professional (ever)              | 0.67   | 0.88 | *     | 0.86  | 0.99  | *     | 0.66 | 0.93 | *     |
| Internal                                       | pt/fam | sd   | alpha | comm  | sd    | alpha |      |      |       |
| Consistencies                                  | •      |      | •     |       |       | •     |      |      |       |
| Quality of<br>Relationship                     | 18.3   | 3.04 | 0.03  | 16.79 | 2.93  | 0.8   |      |      |       |
| Family Social<br>Activities                    | 7.1    | 3.35 | 0.85  | 7.16  | 2.5   | 0.67  |      |      |       |
| Agree on Task<br>Sharing                       | 25.64  | 0.28 | *     | 17.71 | 13.79 | *     |      |      |       |
| Agree Household<br>Tasks                       | 79.9   | 1.41 | *     | 49.82 | 20.26 | *     |      |      |       |
| Family Arguments                               | 3.5    | 2.99 | 0.72  | 3.98  | 2.95  | 0.75  |      |      |       |
| Negative<br>Environment                        | 11.5   | 3.74 | 0.84  | 5.8   | 3.6   | 0.81  |      |      |       |

\* patient <sup>b</sup> family <sup>c</sup> community

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For Children's Health Problems' indices, patients and community members gave similar reports for Physical Health Problems; families reported them slightly more often. Patients and families reported *Psychological Health Problems* slightly less often than did community members. Families and community members had similar scores for *Total Health Problems*, yet patients reported lower scores. All three groups reported similar scores for *Behavioral Problems*. Patients and families reported slightly more *Health-Risk Behaviors* than did community members.

In Life Change Events, patients and families reported fewer Negative Life Change Events in the preceding 3 months and 6 months than did community members. Patients reported slightly more Negative Life Change Events in the past 12 months than did either families or community members. For Exit Events (death of a close friend, separation, divorce, death of a spouse, death of immediate family member (other than spouse), child left home (for school, military service)), patients reported fewer events than did either families or community members. Families showed more Exit Events in the preceeding 6 months than did community members. Patients and families reported considerably fewer Positive Life Change Events than community members in the prior 3 months, 6 months, and 12 months.

For Help Seeking indices, patients and families reported seeing many more mental health professionals in the preceding 12 months and ever, than did the community members. Families reported many more visits to Non-Mental Health Professionals than patients or community members.

For patients and family members who reported each other as the person with whom they had an important relationship, Family-Level indices were evaluated. Study members reported slightly fewer *Family Social Activities* and *Family Arguments*. However, study members reported much higher family agreement on *Task Sharing*, on *Household Tasks*, and *Negative Home Environment* than did the community members. Patients and family members reported slightly higher *Quality of Conjugal Relationships*. The qualitative interviews validated the importance patients and families placed on the *Number of Close Relationships* and *Quality of Conjugal Relationship*. Repeatedly, they commented on how much more they appreciated their spouses, their families, and their friends now. Many shed tears as they discussed those relationships and how the trauma changed their perspective, increasing their awareness of the role significant others play in their lives.

Although there may be no statistical significance in some of the differences between patients. families and community members, some clinical differences are certainly significant. During the qualitative interviews, patients and families shared some of the changes they have experienced as a result of the trauma. Several discussed depressive aspects with which they dealt—having no desire to go out of the house, being too tired to get up and get dressed, secluding themselves from the public because of their looks or feelings. Several discussed taking antidepressants (four family members [7% of HDL-B respondents] and thirteen patients [27% of HDL-B respondents]). Additionally, patients and families reported much higher rates of visits to mental health professionals than did community members, with patients having the highest numbers of visits.

Although patients and families reported slightly more medication use than community members, they consumed considerably less alcohol, less frequently, and had fewer drinking- or smoking-related problems. A possible reason for less use of alcohol or tobacco is that 55% of the area population belongs to the Church of Jesus Christ of Latter-Day Saints (LDS), which strongly discourages drinking and smoking. The HDL-B asked for religious preference. Eight per cent of the patients and 11% of the families reported they were Catholic; 2% of patients and 3% of families were Jewish; 21% of the patients and 19% of the families were Protestant; 35% of the patients and 41% of the families listed 'other'; 15% of the patients and 8% of the families listed no religion, 15% of the patients and 16% of the families wrote in they were LDS; 4% of the patients and 3% of the families described themselves as Christian.

Perhaps because of the LDS, as well as other religious and governmental focus on family in the area, patients and families reported more *Family Social Activities* and *Family Task Sharing* than community members. That may also explain fewer *Social Activities with Friends* and the *Number of Social Network Contacts*. However, many of the respondents were not from the local area, therefore local values would not entirely explain the responses.

The qualitative interviews may provide a better explanation: nearly all the major trauma patients and their family members reported enhanced appreciation of their significant others since the traumatic event. They placed more value on their families than before and described increased awareness of life and its value. This attitude may account for their increased feelings of self-confidence.

#### Research Ouestion 11

"What is the perceived Quality of Life for patients and families post-trauma?"

Using a grounded theory and field research design, the following general questions were asked of the participants: (a) Tell me what it has been like to be (care for) a trauma patient? (b) If you had it to do over, what would you have done differently? (c) What positive things have you experienced? (d) What negative things have you experienced? (e) Tell me about the financial impact this experience has had for you. (f) What would be your advice to others in a similar circumstance? (g) How would you describe your quality of life pre-trauma and post-trauma? The researcher used these initial probes for unstructured interviews to determine patient/family perceptions of the psychosocial costs of trauma. The investigator allowed the participants to steer the interviews to events that were meaningful to them.

The researcher interviewed twenty former major trauma patients, twelve spouses, one non-family significant other, one sister, and four mothers (see Table 1, page 44). Five of the patients, two spouses, the significant other, and the sister were interviewed by telephone. One mother was interviewed without interviewing her son. All in-person interviews took place at the patients' residences, by their choice.

Major trauma patients and their significant others provided a rich description of the trauma experience and how it affected their lives. Most were very articulate, but some seemed less able to verbalize the experience. All were receptive to the researcher. Three lived in areas that made the researcher uncomfortable and glad that the interviews were held during daylight hours. Some participants lived in modest apartments or homes. More participants lived in affluent neighborhoods. One lived in a very spacious home, in an exclusive setting. Regardless of their backgrounds, many had similar experiences.

Patients' answers addressed three common themes: financial effects, physical effects, and psychosocial effects of the trauma. Comments included appreciation for health care and suggestions for others going through similar experiences.

Family members also discussed financial effects and psychosocial effects of the trauma. Additionally, they discussed fear, anger, regrets or nostalgia for lost activities, gratitude for health care, suggestions for others, feelings, and spiritual experiences.

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### Experiences of Major Trauma Patients

#### Patient Financial Effects

Most of the major trauma patients stated they had insurance that covered the charges for their care. There is a low unemployment rate in the sate where the study was performed. Three patients did not have insurance, and five had to pay 20% of their health care expenses. Two patients filed law suits to recover expenses. Several commented on the role of health insurance. As one stated, "Insurance is an important thing in our society. I didn't realize that." Another agreed by saying, "We had been paying for our own health insurance, and it was really a struggle because we were paying almost \$400 a month. I mean, that was a real strain and we were just really considering, 'should we cancel our health insurance?' and finally, we decided no, let's not do that; let's hang in there until we can do something else...luckily. it didn't devastate us financially to have the accident and that was nice."

Many of the major trauma patients claimed they could not work for a long time, and several said their income decreased significantly. Some struggled badly, with one patient losing his home when he was unable to maintain the house payments. One who had just returned to work after four years said, "I've just barely been back to work, now. Just...I wouldn't even call it part time, more like quarter time" (laugh). Another said, "I work just two days a week for four hours a day."

However, other losses were not so severe. One patient, an attorney stated, "I used to primarily be a defense attorney...you get paid by the hour. Now, since the accident, I've become a plaintiff lawyer and you don't get paid by the hour, but you get paid a contingency (fee). I get half of my income from my disability and half of my income that I used to make as a lawyer. So, I sort of make what I made when I got hurt, but I never increased it. I would have made lots more money." All patients said they had paid off all the expenses, although some took a year to do so.

Several complained about the amount of time it took to deal with insurance companies and to see that all the bills were paid. Others said insurance covered only part of the services they received. One, for instance, had extensive dental needs that weren't covered, and another stated his insurance would not cover the Life Flight transport. In irritation at insurance companies, another stated, "But, you know, when you're trying to keep down a job, everything else, and then phone calls have to be made in the normal scheme of things, you really don't have a lot of time or energy to sit down, almost on a weekly basis, because that's what it took to get things finally ironed out, to keep calling and calling and calling."

One summed up the insurance debate when he said, "I kept getting invoiced when I thought that things had been paid, and I kept passing them on to the insurance provider. Then I would get another letter saying that I was overdue. It kept going on and on and on...I had a pile of invoices and I kept getting duplicates and triplicates, lots and lots of paperwork. I kept sending it to the insurance company, and...they have people turn over there. There's no one person to deal with, so I ended up wasting a lot of time."

#### Physical Effects

Generally, post-major-trauma patients reported few continuing physical symptoms. One who experienced a spinal cord injury said, "I have a certain spastic gait, occasionally, and I tire occasionally. I have a constant numbness in my right hand and right leg and knee...and then a heat sensation that is constantly there. It's always there, but you learn to live with it." Several others agreed, and called it being tired, or having no energy. Two years after his trauma, one patient said, "I don't think that I couldn't do it (self care) or didn't know how to do it. I, physically, was unable to do it because I didn't have the energy. I had speech therapists and all kinds of therapists here all the time. I remember them having me write things. You know, I have a few of the samples and I know I could see that at first I wasn't doing too well and you could see. I'd start out all right and my writing would get weaker and weaker and more disjointed and the words weren't coming together right, as they worked with me. I could take three and four minutes and start out my sentences, but they kind of fell apart. I remember all that. I think it was more that I just didn't have enough energy and that took me a long, long time."

Another, three years post-trauma lamented, "I tire easily...You have to always be more productive if you want to continue making a lot more money...I don't have the energy."

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Others reported debilitating head aches. One patient, who was six months post-trauma, said, "I hit my head into the gear shift. That's how I got water in the brain. So, the doctor was just telling me that it's normal to have headaches, and he gave me some pain pills and stuff...it seems like when I bend over. I get it sometimes, picking something off the ground. If I do it a lot, I can't work." Another, who was five years post-trauma said, "Sometimes the headaches are really bad. But, I've noticed that I always have a headache, because a couple of times, it's gone away and I think, 'What's different?' You know, I mean. it's the norm to always have a headache, but I'm kind of tolerant of it, you know." Another patient who is three years post-trauma said, "I still suffer from a daily headache, that just never is gone. Some days it's not quite consuming and other days...it's just always there."

Some of those who had headaches also mentioned dizziness. An example is the patient, who, five years post-trauma, said, "...every day when I get out of bed, I'm dizzy. My husband laughs at me when I get up in the middle of the night to go to the bathroom. I do this (she held out her arms) to balance myself. It's just kinda one of those things that you do." Another reported similar feelings; "There are some dizzy times. I'm dizzy, now....right now, I'm going through the third week, where it's been there, all three weeks. It's just been all...so every time I get out of bed, I have to take a little time. I have to sit on the edge of the bed." Another patient, six months post-trauma noted, "I'd get dizzy when I stood up all the time and all that. So I couldn't do nothing."

Some patients complained of continuing pain. Three years after the trauma, a patient described it, "(it was) like an electric cord." Another, after the same interval said, "I can't even walk comfortably now. I can't sit for long periods of time."

Few of the major trauma patients continued to have dramatic physical sequelae. One of those described above has a spastic gait, another walks with a slight limp. Still another uses a wheelchair most of the time. although he can get around the house without it. He is able to work five hours a day, three days a week. Two stated they had some hearing loss.

The patient with the most physical problems described them clearly. After having 25 surgeries in two years to repair orthopedic damage, at the time of the interview, she was in a neck brace from the latest

surgery, which she declares is the last. She said, "I do need some help grocery shopping, because it is hard on my lungs to walk that far through a grocery store and then stand in line...the mall is just so huge for me to walk through, so I take my wheelchair, and I can't go alone because I can't lift it in and out of the car and so someone will go with me. I have all sorts of gear to take me up the stairs. Post earrings are hard--the kind that just go through are easier--because this arm doesn't bend. My elbow doesn't bend at all, so everything that I do with my face or my hair...has to be done with one hand...buttons, necklaces, things like that. Special toilet seats, special sticks with hooks on them to help me get dressed, things to help me put my socks on. Long-handled hairbrush, and a toothbrush extension. But I have found ways to do things for myself and by myself, and I can take care of my family and do my housework. I can't carry my laundry up from the basement, but I go down and am able to do laundry." She and her husband had a chair rail put on their stairs to take her up to the bedroom areas. She is able to work at her former job four hours a day on two days a week.

#### Functional Effects

<u>My Alzheimers hit on June 29.</u> Many patients complained of a memory loss. Some suffered head injuries, but many had not. Even without a head injury, one patient said, "It's on the tip of my tongue, but I can't pull it out. It may come, but it isn't here."

Another agreed, saying, "I didn't have any head injury. My memory--I noticed my memory is not what it should be. I was part of the study, ARDS survivors at the hospital, and they did an IQ test at like, the 4-month point and at the 2-year point. And I scored very well, very high on that. So they--it looked to them like I had all my marbles. Still, I notice my memory's just a little slower than it used to be. I'll have a hard time, sometimes, remembering a word. It will take me five seconds, when it used to be right there." One stated, "My memory is not the greatest. I can't remember last names. And I have to write things down, or I totally forget them." Other patients observed that people at work reminded them of previous conversations, but the patients did not recall those episodes. One said, "they remind me of that at work all the time. 'You need to focus more. You need to...', So, I'm starting to write down everything, and I feel like I'm 80 years old. My family will say, 'You just told me that five minutes ago.' You know, I'll ask a question and (they say), 'we just told you that. We've told you that five times.' I don't know (what really happens)." Ultimately, another described it this way, "My Alzheimers hit on June 29."

It's like draggin' a jeep through the mud. Many of the patients complained about decreased concentration capacity. One said, "the...issue was expectations for myself. Having to deal with those deficits and knowing what you were able to do before, now all of a sudden it's like dragging a jeep through the mud. It takes a long time--head trauma. (Wife) finally recognized when I needed to be alone. I would go into my room or I would go downstairs in the storage room. I would just sit. It was pitch black dark down there, so I could think and I could unscramble all the mess that was going on inside my noggin. It was like someone put an eggbeater inside my head. It took awhile to filter out what happened to me and what was other people's situations."

Another concurred: "When there are distractions, when there is more than one thing going on at a time, I can't follow both of them. I do lose my train of thought. Like with the kids, they'll say I totally forgot something, and I'll say, 'was I looking directly at you when you told me this?' Did you look at me and know that I heard you, because, if something else was going on, I missed it." Another stated the same idea, then demonstrated it. During our interview, the doorbell rang and the phone rang. The patient could not differentiate which happened first, nor could she continue with our discussion.

Another described how hard it is; "The insensitivity and apathy of others. It comes back to their expectations, because I may appear well. I think the worst has been just frustrating, with people not understanding, because I look normal. My family knows only 10% of me works. It gets a little frustrating that they don't realize, after four years, these are my problems and they are not aware of them yet."

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However, another appreciated how friends adapted. She said, "If we get together to play a game, or something like that, they all know that they have to be quiet, so I can count my points. If anyone says another number, I'm just totally lost. If fact, a lot of times, they just take them from me and count them for me, because I can't concentrate, with the noise around me."

One brain injured patient explained, "There's no chalkboard for the brain that shows you exactly what's going on." Another mild brain injury patient, who is also a rehabilitation doctor working with brain injured people all the time, concurred. He said, "Brain injured folks don't get better quick, so it's kind of frustrating. I was five months out and I was still impaired and knew it and thought, 'this is tough.' I compared it to others (patients). It gave me a real appreciation for their struggles...come on guys, it's going to take a while."

## Psychosocial effects

Real powerful stuff. Although the major trauma patients suffered some physical setbacks, most of the experiences they related fell into psychosocial areas. All underwent life-changing events, some more dramatic than others. Some changes took place immediately after the accident; others continue to unfold. One described, "an awakening experience. It's life altering." Another, in contemplation, mused, "Well, I think I look at life a whole lot differently than I did before." Yet a third emphatically stated, "I mean really grasp onto it as an event that is a significant one in your life. You may or may not have addressed it, but it will change your life. Make it important...It's a rare opportunity to grasp onto some real powerful stuff that's going on...Don't ignore it. Don't minimize. Grab it."

When I woke up and saw tiles on the ceiling, I thought, this isn't heaven. Several post-trauma patients declared they thought they would die or were dead. One said, "When that kid hit me from the back, the first thought that came to my mind was. 'Say goodbye to my family.' That was the very first, because I knew I wasn't going to survive that. There's no way, because there were cars in every lane, and I missed about three of them, from the notes that I read in the reports, just inches, and then hit head-on with the semi

loaded with sheet rock and towing a forklift . . . Then, when I woke up and saw tiles on the ceiling. I thought, this isn't heaven. (I) just was so glad to be alive."

Another stated, "Meanwhile, I'm bleeding and everyone that came to the scene walked away, saying, 'she's dead.' And then there was this one lady that said she came and sat there on the ground beside me until the people got there, the rescue people, and she said I asked her, 'Am I alive?' Apparently. I had heard everybody saying I was dead so I couldn't figure out for myself where I was here on earth or some other place (laugh)."

Yet another declared, "I was so afraid that I was going to die. You know, if I would have been dead, then there wouldn't be anybody there for me. That really got me...we got married, like, the week after (hospital discharge)."

Along slightly different lines, one expressed it this way; "one thing that started fairly soon after my recovery was a need to recapture that missing time...It was almost an urgency. I was gone for awhile (unconscious) and I'm uncomfortable with that."

One patient wished she would die. She said, "When I was at my very lowest point, I had a dream that I was angry at the woman who hit me for dying and I was feeling sorry for myself, and I decided that I wanted to die. And in this dream, because it was so difficult at that time for me to breathe, even with my ventilator, I felt like if I held my breath, I could take my own life. That was the only way I could because I was totally helpless. But it became obvious to me in this dream that I didn't want to die, that my family needed me still and I wanted to be here."

Living life in the left lane. Some discussed their previous lifestyles, including risk taking behaviors. One said, "My entire past driving career was speeding tickets. I was living life in the left lane, with my foot to the floor...I basically moved away from the edge. As I told you, I had all those speeding tickets--but now, I'm copesthetic."

One stated, "It's mellowed me out a little bit. It took me out of mountain biking, made me less aggressive and less competitive. That's mellowing me out...might have been a positive thing, because I could have gone on to do worse, I guess." Along these same lines, another said, "My priorities are different...not so much play. My lifestyle's changed." Another agreed, "I am different. It was like a rebirth--everything was in slow motion...It's over two years ago and I don't have...I'm not like I was."

Yet another, not willing to call it 'risk taking,' clarified it as "calculated risks." He stated, "You're at the elements of what gravity and dynamics and physics is going to deal you. I love recreation. sky diving, rock climbing, hot air ballooning, river running, scuba diving--all that good stuff....You can always modify the recreation..."

One patient said, "I learned a lesson and maybe, perhaps, that I'm not invincible...I'm going to think about the consequences, maybe." Yet another claimed, "I am more cautious. So that I guess I have maybe been aware of risk taking a little bit more, not that I hide in the back room." One summed it nicely. when he said, "You know those stickers kids have on their cars, 'No Fear?' I have one: 'KNOW Fear.' It's just to understand what you expose yourself to. (thinking) It'll never happen to me. It doesn't mean I'm a coward, it's just that I'm aware of the risks and I'm just a little bit more cautious. It probably saved my life. I've quit living on the rough edge. I was splintered, fragmented. (Now) I am very disciplined." These experiences reflect some lifestyle changes. Patients experienced other changes as well.

Don't minimize. In discussing the effect the trauma would have on a person, one post-trauma patient emphatically stated, "Don't ignore it. Don't minimize. I mean really grasp onto it as an event...that will change your life. Really actively get involved in what's happening week to week or day to day with yourself." One patient suggested, "If you have any questions and you are able to think lucidly, you should certainly ask someone." Many suggested one should not return to work too fast, but to take more time in the healing process.

One post-trauma patient who felt he did not receive the best health care, nor complete help from his insurance company, stated: "Make sure that your doctors don't mess with you. And don't let the insurance company push you into anything. Get a second opinion before you do anything." Another stated she would change doctors. "He released me from the hospital, just on my own. No one said, 'yes, you had a head injury.' I always thought I needed some help." Others felt that a Family Support Group in the Intensive Care waiting room would be helpful. Most post-trauma patients were positive about the health care they received and focused on suggestions to make recovery easier. Several post-trauma patients gave specific recommendations how to do that. One said, "Don't let it get to you, mentally." Some reported they had to take antidepressants and suggested mental health and cognitive counseling: "A friend picked up on the cognitive changes. He (got) me into counseling." Another stated, "My advice would be to have faith and pray for strength to get through it and learn from it, and be able to find the positive, good things. That attitude...Attitude is like 99.9% of a lot of things." Validating that counsel, another said, "I guess the advice I would have is to look on the positive side. To take the advice of the doctors and nurses and give it your best shot."

Service on a silver platter, rather than a styrofoam plate. Most of the post-trauma patients volunteered comments about how good their care was while they were in the hospital. One described it as, "Service on a silver platter, rather than a Styrofoam plate." Another said, "I wanted so bad to express my thanks and appreciation to them for all they did for me, and for taking the time to educate themselves so that they were in a position that they were able to help...my life was literally saved by these people."

Other comments support these statements: "LDS hospital...they were the best for me. And my orthopedic surgeon, I couldn't have selected anyone better than he was. I just, I was blessed to have the best doctors." Another patient said, "I think one of the positive things was certain medical profession people...they are people that are very talented and very caring, who help a lot, who understand, really, the only people. Rehab were the ones who really understood what you were going through. Very supportive. One of the neurosurgeons was exceptional."

Another stated, "I got such good care and immediate attention when I had my accident, when I was in the hospital that I think that's why I'm where I am today." And another: "I have to say I was very happy with my care and I was also quite lucky. If the accident had to happen somewhere, that it happened where it did happen, where I was able to get really really good care. Especially that I got on initial contact there at the hospital from the ER people."

One patient expressed surprise at the attitudes of the health care providers. He said, "The nurses there really enjoyed their work. That was enlightening for me to see."

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However, a few post-trauma patients felt they did not receive adequate care. One stated. "One night in ICU, I didn't feel like the care I was getting from one nurse was okay. I had this breathing tube and I felt like I was choking. He didn't suction me and it was very scary." Another said, "...And it was just the doctors that pushed you around and everything. They really don't listen to you, I don't think."

<u>Pity Party.</u> Nearly all the post-trauma patients talked about the change in their perspective. One said, "I don't feel it was all that very bad, I guess. It was good for perspective. Another said, "People are always saying, 'how are you?' I say I'm great. I mean, really given the choice, do I want to be great or do I want to be sad and unhappy and ornery."

One patient, who had been hit head-on by a person who died in the accident said, "I haven't been bitter about it, as far as the woman who hit me. My husband has been angry at her, because of seeing things that I've gone through, and seeing the struggles, he really has. But there was a time when I was very, very sick in the hospital that I was angry because she had died and because I hadn't. Early on in my recovery, when I was still in ICU, and I was sort of feeling sorry for myself, I came to a decision, a conscious decision, that I would not feel sorry for myself. That I would work very hard and do whatever it took to get my life back."

Another, whose mother-in-law was driving in the accident that killed her son said, "I never have blamed her for it (the accident), but I went through a period where everything she did and said just kind of bothered me. And I don't know if that was just...because I like my mother-in-law as a person and she had never bothered me before that. And I think I realized that it was bugging me. I guess I kind of analyzed it or something and just realized that maybe part of me <u>was</u> blaming her. Then, after that, I was able to let it go."

One, the victim of an auto-pedestrian accident discussed her emotions about the event: "You just go on minding your own business and you're in the crosswalk and watching for cars, and some stupid seventeen year-old kid that's had several accidents before and hadn't had his driver's license taken away...and it just works out, and ends up where you get hit. His family sent a planter full of plants and it gave me great pleasure to chuck that in the garbage as hard as I could. I mean, it was almost a healing thing. That helped me, but I just, I had to make the best of it. I just had to go on. I mean, I could sit and stew about it and, you know, could still be bitter, but it wouldn't do me any good. So I just decided that I needed to make the best and go on. It was really hard to talk about it for a long time."

Yet another related her experience after the accident: "You know, the (physical) therapist would take me down to Temple Square and I had this head all shaved bald and these big scars and scabs and stitches and everything in my head. I had a feeding tube sticking up out of my nose and they've got this big strap around my waste and a handle on the back. They're walking me around Temple Square. And the looks! Oh, my stars! I, at first, kind of forgot that I was peculiar looking, I was so excited to see all the beautiful flowers and things. But after two or three people would be walking along and somebody would stare in my direction and I'd look up to smile and say, 'hello,' and they'd cringe and jump...I thought, wow. I think I'll just keep my eyes here on the ground. I'm not even going to look up, 'cause I'm frightening people. I didn't like what I saw in the mirror, either. It scared me...My family was very loving and supportive of me...and my friends. I mean in a way, it was a wonderful, almost a wonderful gift of blessings, the accident. Because, for the first time in my life, I realized that people really loved me and cared about me."

Another expressed his change in perspective with this: "Can I finish by telling you a story? It was a bad day. I was having a 'pity' party. I was stopped at a stop light in downtown Houston, when I saw a young man--really sharp--crisp blue blazer, walking down the street. He was sharp. He had a smile on his face. And then he turned the corner and I saw his other sleeve tucked in his pocket. He had no arm. I thought, if he can be happy with one arm, I can be happy with two arms. I've gained a great insight--I was gifted for this to happen this way--to help me slow down."

Patient Spiritual Experiences. Other post-trauma patients discussed the spiritual dimensions of their accident. One said, "(It) also gives me a lot of spirituality. I think it makes you think there is a God. Once you've survived a terrible event, you continue to live..." Another agreed. She said, "I know that my Heavenly Father played a great big part in it, and we know, ultimately, that that made the difference."

Yet another patient felt there was a higher purpose in her accident. She said, "I always feel there's a purpose for everything to happen...I think that the whole purpose for this whole thing that happened was to teach me some patience. I believe there was somebody there with me...I really do. Reinforcement and life on this earth and that you better clean up your act and do what's right, now, because you never know when you're going to be taken."

As one patient reflected on the experience, he said, "I was there, but I wasn't there. I'm--even preaccident I have always been really fascinated with...but it's spiritual issues or infinity or a lot of those unanswered subjective things that we can't define. But for a while, I was elsewhere."

The young mother who lost a child and a sister-in-law in the accident stated, "I remember coming out of the whole experience with a sense of peace that everything was okay. A lot of what has made it bearable is our faith that we'll see that person again, and it will be okay because we can be together, again." One stated, "I understood, finally, how much my Father in Heaven loves me."

It was a wonderful gift of blessings. Nearly all the post-trauma patients discussed their heightened appreciation for those around them. One said, "I couldn't believe it, when I finally was aware of what was going on. The people that called and came and sent cards and flowers. I had no clue that people would even notice, let alone care what happed to me, other than my own family." In validation, another said, "I have a lot of family around me, who helped me out. My whole family was able to come to the hospital and see me. My parents were living in Saudi Arabia at the time, and they were able to come. (Then,)During the days when I couldn't take care of myself, I stayed with my husband's aunt. She was really good to help me out and help take care of me."

Another agreed. She said, "People have been wonderful. They've been very nice to go way out of their way if I needed help. It's been difficult to learn how to do that, and to feel that it's okay. But that doesn't bother me any more...It's had a positive effect on my extended family as well as my immediate family, as far as how close we are. My mother or my daughter have been very good, or my sister, to go grocery shopping with me, each week. It's something I don't do by myself."

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"My husband, as well as myself, we have both been air lifted...So, for a while, I was taking care of him and then, he was on the other end of the line. Both of those had a very positive effect in our marriage. My sister and brother and I have gotten closer, (and) my parents. The boys are good at ironing their shirts. My daughter was 16...getting her brothers up for school, making my husband's lunch, and things like that. They've done really well with everything."

Another commented on the help from others. "We had a lot of friends that came over and helped. We had some neighbors...she would check on me all the time."

Even the post-trauma patient who cannot communicate well discussed the help he gets from others. "It's my neighbor. We're going to a show, going to stores, and everything...And my friend--she sees (saw) me in Rehab. The only friend. She was working there and she sees me and she understands me."

Many discussed the need for family and friends to 'be there for me'. One patient who was single at the time of the accident said, "You know, if I would have been dead, then there wouldn't be anybody there for me. Maybe it's nothing, but I want somebody there for me. I think that's the big difference. She (fiancé then, wife now) was there the whole time.

In contrast, one post-trauma patient felt he did not have support or understanding from family members, though his friends were helpful. "The toughest part of my accident, wasn't so much my accident. It was dealing with the people around me. The insensitivity, what's the adjective I'm looking for, apathy. Mostly my in-laws, and inappropriate things that were going on, and so forth. I had enough problems as it were to deal with my own trauma, with my own deficit, without having to deal with all this other...extracurricular, external problems that really shouldn't have been thrown my way. All the family issues. It's nice to feel, to sense, to see and feel that someone has a genuine concern for people. I didn't see it. Never. I still don't."

Patient quality of life. Nearly all the post-trauma patients felt the quality of their lives was better, after the accident than before. However, some said the quality was about the same, but activities had changed. One reported, "but there's a slow part. I can't party as much."

Yet another declared, "The quality of my life is better now. Then I took things for granted. Now I look at my friends and that support and the love that I had from people. I will never take things like that for granted ever again."

Another agreed. "I feel like, before the accident I had a good life and I was happy. But since the accident, I am much more appreciative of everything than I was before. I loved my family before. I just love them even more now." Yet another said, "Before the accident it was pretty good. Right after, the accident, I guess it was even better. I had a better mental attitude."

Many equated quality with happiness and state of mind. One said, "I was happy before, but I'm happier now. I was a stressful person, goal oriented, make things happen, hyper. Now, I'm tranquil. This has given me years of life. One main thing I learned...How things can happen in a split second. Life is very dear."

One who continues to have physical difficulties stated, "physically, it's more of a struggle, but I think by putting it into perspective, ...And, umm, I think I put those important things in my life back into perspective, which makes my life more whole." Another described it: "I guess, minus skiing, that I just lived day by day (before.) Now, I spend time with friends. I guess I don't look at the limited mobility as a detractor. I'm trying to have a positive outlook."

Upon reflection, one said, "We've had a lot of success in terms of professional growth and advancement and family. Subsequently (we) have also continued to be comfortable and successful. So, I think my quality of life, in many regards, was good before the accident. I think my quality has improved, although it has been more difficult...I think it just made us more aware that we remain lucky and need to not forget that the clock is spinning, and you never know when the bell is going to ring."

Agreeing, another stated, "I would say that the quality is better now, even though it is more difficult, because of the things that we have learned and the relationships, how much closer we all are. It's not as physical as it used to be, but the things that mean a lot are still there, and they mean more to me. So I would definitely say that the quality is better, though it was good before. And I do feel like I've lived two lives, two very different lives. When we talk about things, we refer to them as 'before the accident' or 'since the accident'."

## **Experiences of Family Members**

Family members discussed the effect their major trauma patients' accident had on them. The accidents covered a gamut of injuries; head injuries, major abdominal injuries, orthopedic injuries, and combinations of several kinds of injuries, which required different adaptations on the part of the family members. Many cried during the interviews, some with tears of gladness, some as they recounted their spiritual experiences, most with tears of sadness.

Family members also discussed financial effects and psychosocial effects for them, as a result of their major trauma patients' accident. They added additional sub-categories (fear, anger, and feelings) to the psychosocial effects.

## Family Financial Effects

Some family members experienced severe financial setbacks, due to the accident. Many had to have new cars, although their car insurance companies did not pay the entire amount required. One husband took an extra job to cover expenses. He said, "She wasn't in a position to go out and get a job, herself. I realize that. None of our kids had come of an age where they could contribute, in a financial way. So, what do you do? You go out there and find another job or two or three. You do whatever you have to do."

A mother had to quit her job to care for her son, after he was released from rehabilitation. Another mother reflected back to the financial distress; "I remember trying to juggle his sister's birthday party around. He had just barely gotten home from the hospital. It was the first part of December. And I remember the finances of it. Thinking, Oh God, how am I going to manage this. You're budgeted and you have, maybe \$40 left over at the end of the month. I thought, one way or another, I will figure it out. And I remember going to my little brother and saying, "I've got to have a short term loan." A husband reported, "It probably cost us \$40,000-\$50,000 by the time it was over...probably more than that, when you consider time off for headaches. We rely on (her) income. We'd have had to make some serious adjustments, had she not been able to go back to work. Take it one day at a time and move on. You know, you can't dwell on what it cost you. You really can't"

A wife stated, "He lost his job and that was semi-related to the accident. Luckily, he had been there long enough that he had his 401 built up and we just took that out. It hurt us on taxes, this year, but it helped us out. Plus, I got laid off in August from my job and I was getting unemployment. So we had some income coming in."

Most family members stated they had good insurance that covered most of the expenses. One reported, "We had excellent insurance, so our out-of-pocket (expense) was \$2500, from almost \$100,000 worth of medical bills, including home health, which was expensive. Another said, "The only extra cost was flying us home, and that was on a private jet, but my insurance covered it."

Others did not fare as well with insurance One family member reported, "(He) had insurance, but they said he was not covered for air ambulance. He had an attorney who was a friend of ours...they paid it. We were able to pay off the other debts that were our responsibility. They covered 80% and we had 20%, then they dropped us and we had to get another insurance company. He had to be followed up, but this was a preexisting problem, so they didn't cover it. They (follow up) were all out-of -pocket expenses. It might have taken a year, but we got everything paid off. I would rather pay that off than a funeral expense."

Another stated, "You have to fight for everything from the doctors and the insurance, and everything. They doubt everything you say. They say, they think...there's so many people on workmen's comp., that they think you're lying to them, so you can stay on it forever."

Others, with better financial backgrounds fared better. As one reported, "We were fortunate that we had resources. He probably went back to work sooner than he should have. But we were fine, financially, so it didn't impact us as much as it could have someone else.

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#### Family Psychosocial Effects

<u>Family feelings.</u> One family member stated, "You feel like the doctors are God or you feel like your vote doesn't count. And I think a lot of times it doesn't. I really felt like I was at their mercy. You have to push for it. But my dad was a doctor and my husband is a doctor, so I sort of knew I could get what I wanted, if I stamped my foot."

Another, who is a social worker on the east coast said, "It was, to me, a first hand lesson of being on the other side of what it's like to get things pre-approved, pre-certified, you know, up front in the admissions office. I remember having a big fight with the people at the health plan, his health plan...it's not possible that the two primary care docs could talk to, you know, the emergency surgeon. You know, they get approval for everything they've got to do. I mean, the guy's a mess...somebody at your end explained what a Level I Trauma was. Then they stopped trying to act like he had cut his finger and just needed a few stitches."

Reflecting back on the whole experience, another replied, "I feel so much stronger inside myself. I feel like I could handle just about anything, emotionally or physically. If we had some big huge disaster, I feel like it wouldn't be a disaster. I've been through a disaster. We could live without a home, we could live without whatever, and I could handle it, emotionally, somehow.

A mother, whose son had several severe accidents over a period of time reported, "I talked to God and I said, 'why, all these things keep happening to him and you keep leaving him here to suffer? To suffer more and more? I guess there's a reason. I'm glad He's let him stay here with us for so long. Sometimes you wonder if it was fair, maybe he should have gone the first time and missed all the others."

I was so scared. Nearly all of the family members discussed their initial fear that their patient would die, or about the problems that came up, after the patient was home from the hospital. "In the beginning I was so scared. (They) were trying to keep him alive until (they) got to the hospital. I just freaked. (When I got to the hospital) he was just screaming. I just kind of held him and he calmed right down. The first 24 hours were scary. But I sort of had an inner sense he was going to be okay." Another agreed; "Right up front, in the beginning, right after the accident, we weren't sure he was going to make it. As he started to progress, we weren't so worried." However, another reported, "They called me. All they

said was she had been hit by a car. I didn't know the extent of the injuries. To be honest, I expected it to be less. When I got there and realized how serious it was...I just went from there."

One, newly engaged at the time of the accident, said, "It was hell, to put it bluntly. It was very traumatic to me, because he was what I waited for, my whole life. Then I thought I was going to lose him. So, it was very, very hard."

Another stated, "He's (the patient) a Rehab doctor. So, that was the hardest part, just knowing all the possibilities and things like that. Probably a little bit of knowledge was bad because I realized what could happen."

A wife, whose husband suffered a severe head injury stated, "I didn't know what a head injury was...I pictured a bump on the head. And then, of course, slowly reality sinks in and (you) deal with him being in a coma. I didn't know what level he would stop progressing. I had no idea if he would end up to be a vegetable." Another agreed, "At the outset, we had no idea whether she would be brain damaged or anything, and so, obviously, we lucked out." Yet another stated, "I was fearful, but I wouldn't allow myself to have bad thoughts, so I kept willing it away.

As families and patients tried to resume normal life, things continued to reinforce their earlier fears. One said, "I had to take my son back to California (tears) for burial services and burial services for my sister. When I came back to Salt Lake, her mom met me at the airport and said, 'she may not be there.' Every time that she's gone and she's not home on time...I really get nervous and think something has happened."

Anger. Many reflected on some of the negative feelings they experienced, and evaluated their emotions. One advised, "Don't be mad. Don't hold grudges against other people. Life is so temporary. Sometimes accidents are just that...there are just accidents."

Another reported, "I got pretty angry. Try and compensate her for what she's gone through. She ended up getting the house of the woman that hit her, in a law suit, and it's a real fixer upper. And here we are 2 ½ years later, and I'm still over there working on that house. Some nights, when I'm there by myself. I hate that woman. I feel like she's still affecting our lives, but I know it's going to be over soon." An anguished husband stated, "Well at the time, I thought everything was caving in around me. you know. Why her? Why us? Why not me? I fell to my knees many nights, every night, for a long time. I was mad. Why her? What has she done wrong? I dismissed that pretty quick! What have I done wrong. I couldn't dismiss that as quickly (laugh)! Once you accept that you're not being punished and she's not being punished, things will go a lot smoother for you."

One family member, a mother said, "At first I thought, you know. I should have done something or I shouldn't have done something. And I didn't even know what it was. I kind of kicked myself for a couple of days, feeling real guilty about it."

Yeah, it was tough. Many family members experienced heart-wrenching emotions while their patient was in the hospital. A husband said, "People would come up to me and say. "I don't know how you do it,' and I'd just say, what choice do I have? I wanted to be there (at the hospital). Even though...when she was unconscious at the ICU, I wanted to be there, so (I) always had that desire to be with her pulling at me. I'm sure I neglected my children. There were so many things happening all the time, with her condition, that I didn't want to be home with the kids watching TV when something big happened. I made the trip every morning, every lunch, and night. Sometimes, I'd make the trip at night, twice, because I'd come up with the kids and they'd have to go, so I would take them home and then I'd want to go back."

One husband lost a son and his sister in his wife's accident. He reported, "It was tough, because both my mom and my wife....my mom had been awake the whole time. She was aware (of what happened). I had to tell my mom that my son and (my) sister had passed away."

Another stated, "It was hard to make the physicians understand that I was part of this and they weren't going to just say what was going to be done, without talking to me. I finally took this one intern out into the hall and was stamping my foot and shaking my finger. 'I'm not used to being treated this way. You stop it, right now.' I think that was the hardest part."

After the patients returned home, family members faced other concerns. One said, "Yeah, it was tough. I'd have to get up early enough in the morning to get her dressed and get her downstairs and get the kids up and all that, before I took off for work. At first, when she first came home, it was hard because she couldn't dress herself, she couldn't bathe herself, we had to help her up and down the stairs. She couldn't sit down or stand up by herself, she took a lot of care."

Another added, "It's really hard to see someone you're so close to be incapable of doing the things that are routine for us." A mother said, "It's been kinda hard. It was a year now, in March and it's still upsetting, because he's not the same as he used to be (crying) and it just really hurts."

A wife reported, "It's been really hard watching him and all the hell he went through. He doesn't remember half of it. He has a lot of problems he doesn't realize he has. We're just proud of everything he has done. It has not been easy. And you have to fight for everything."

A young wife, struggling to care for her husband and a new baby said, "I was just stressed to the max. I couldn't even stand up, 'cause...I don't know. I guess somewhere in the back of your mind you figure he'll come home and he'll be fine. It doesn't happen like that at all...But I didn't want it to cause more stress on him and it caused an incredible stress on me, and I just didn't know if I could handle it."

Similarly, a mother said. "That's one of the hardest things, I think, for a parent to accept what has happened and to look to the future and see how it's going to be, and that it's not just a short term thing. That it's going to be very long term. And the stress on both parents, and especially when you have a head injury. The agitation levels just stay high all the time. So, I tried to, basically, to hold it together. But, after almost four years, I'm pretty well drained. I just don't know what else to do. It's rough. It's really rough on the family."

Another mother said, "It was hard for me, because his dad and I are divorced. Trying to support him and me and my other three girls that I had at the time, it was just really hard. He went back to being a child.

Gratitude for health care. Nearly all the family members who were interviewed felt they received exceptional health care. One said, "We realized how great the health care is here. The hospital treated us very well. The people were attentive They took such good care of her. I've talked to a lot of other people about trauma, since this accident. We are awful lucky to live so close to Salt Lake, with the two super trauma units. I suspect they saved her life." Another reported, "The staff up there at the hospital are good...Someone came to me the first day, a social worker...And their surgeons and their nurses. I mean, everybody that dealt with (the patient), they were all willing to explain what was going on. And they were really sensitive, too. They would take the time to answer questions. It even got to the point that we asked such specific questions about her condition that the nurses said, look, here's the computer. Here's how you change screens. If you want to see what her BUN (blood urea nitrogen) is, look, there it is. If you want to look at her HCT (hematocrit), there it is. I remember one time that the doctor was telling me that she had ARDS (adult respiratory distress syndrome). And I didn't know what ARDS was, but I knew it wasn't good from the look on his face. He could tell that I'd heard about as much as I could handle. And he said, we'll just talk about this, tomorrow. I appreciated that, a lot."

A husband declared, "I couldn't ask for better medical attention. The medical attention she had with the paramedics and life flight, the doctors and nurses in the trauma unit up there, was just fantastic. All those in physical therapy and Rehab, occupational, speech, physical therapists, they were just great."

One family member said, "I didn't know what to expect, but I was really impressed. I don't know whether or not they, the emergency area up at the ski resort is connected with Life Flight, which is connected with the hospital. But obviously, from the ski patrol, who know what they were doing, to the people in the emergency department...The hospital that I'm at is affiliated with Harvard, and we're tied into all of the University affiliated hospitals. The hospitals are ranked number one and two in the country. You wonder what happens when you get away. Somehow, I just don't think of Salt Lake as being comparable to, you know, Mass. General Hospital, but that's just not true. I have nothing but the highest regard. The nurses were wonderful. I was really amazed. You know, the nurses there were fine, if not finer...you know, have a slightly different attitude. It depends on how important they are."

<u>Had to provide care.</u> Many family members cared for their major trauma patient after discharge from the hospital, or rehabilitation. Some helped with the care while their patients was still in the hospital. One said, "At first, when she was still in the hospital, I'd give her a shower or brush her teeth. It was very

troublesome. I wasn't sure she would come through as well as she has. I took her home to take care of her. I guess taking care of her helped me to get through."

Another reported, "At first, when she first came home, it was hard, because she couldn't dress herself, she couldn't bathe herself. We had to help her up and down the stairs (split level house). She couldn't sit down or stand up by herself. She took a lot of care." Another had a similar experience: "He could mostly take care of himself. He couldn't zip a zipper, put his shoes on, anything like that. We had to balance him, for a while. He was just slow and he did real good. It just took a long time."

One husband commented on the amount of work and emotional energy it took to provide care for his wife. "She could pretty much feed herself, for the most part, but as far as everything else, just moving around the house, getting dressed, washing her hair, things like that..She's always helped me, and, all of a sudden, you know, I'm it. We had a lot of help with the health care (at home), but just so much fell back on me, or one of our children. They (home health) would come between 7:30 and 8:30 in the morning. I would try to go to work and come home as soon as I could, to give them some relief. They had been here for six to nine hours, by the time I got here. But, they were used to it, and I wasn't."

A mother reported, "I took care of him from May, until all that winter. All that summer and winter. That was maybe about seven months. I had to take care of him, because he would fall asleep and he would wet the bed and he would even mess the bed, mess his pants, and it was really hard there, for awhile. Then he started drinking, you know, drinking, which he couldn't handle. We would find him outside, when I'd come home from work, 'cause I'd come home at 1:30 in the morning. I'd come home from work and I'd find him outside, all drunk and passed out, outside, even in the wintertime, and he would be all..messed in his pants. Oh, it would just be so disgusting.

Regrets. Many family members expressed regret for the part of their lives that is gone. A husband reported, "She likes the outdoors, she loves the mountains, she liked climbing, she liked back-packing, she liked playing tennis. She liked to bike ride. And really, she just can't do any of that anymore, and that has been tough. Because I'm still, we're both still relatively young, I think. 40 years old. When I was 20, I thought 40 was old. I don't think that's so old, now. I think I've got a lot of life left in me. You know, I

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have friends that are 50-plus that are still rock climbing and still doing those things. And I want to do that, but when I do, it pulls me away from her. And it used to be that those things drew us together, instead of pull us apart."

Another agreed: "We're not able to do as many physical things. Backpacking and things like that, we've avoided. We have to worry a little about bumping her head. I don't think it would ever relapse into something serious, but it might take a couple of days for her to get over the headache. I've still gone with my friends and things. I think that's something that we would have done together that we just haven't done."

Yet another husband stated, "I want to do more with her, and I want to be more actively involved with her. Now I'm getting of the age where I would like to have that companion to do it with, but she's not physically able to do it, and so I miss that. That's a big change that has affected me, because I'd like to have her with me."

A wife also felt the same concerns. She said, "Before, we used to do a lot more together, like more active, when we traveled. When we would go on vacations, we used to do a lot of walking through towns and things like that. Now, when we go on vacations, we take tours on a bus. He can walk, but it's difficult. He gets tired, very easily. We look at the tours to take, and then we get to see places, easier than if we were walking.

Another lamented, "He couldn't be there for me, at all, and hasn't been, you know...hasn't been there emotionally, at all. 'Cause he can't be there for himself...He's basically a very much different person than I married, and always will be. But, it's up to me to get to know that person, if I want to be with him. But, because of how I believe, being LDS...and something inside of me, I know who he is, inside. I just keep reminding myself that, through it all, he doesn't mean to do this, he doesn't mean it to sound like this."

A husband expressed similar concerns: "We're trying to justify it (her behavior) trying to say, she's got a mental thing here. She's forgetful there. But you know, other people, they look at it, like, she's really rude, or she doesn't care, those kinds of things. Not everyone can understand it, so we have to deal with that. It's hard to take. Especially when I knew her before the accident. She was always caring, considerate to other people.

A sister, after having the patient in her home, said, "there are some changes in living arrangements for him. He has been living with my husband and I, for about six months, now. He became very reclusive. for want of a better word. He would sit in front of the TV, where, before, he was very much against watching TV. Or, spending a lot of time in front of his computer.

A mother, whose son had a head injury reported, "in the beginning, he had some friends who were very dedicated in coming over and being with him. But, now, it's down to pretty much all of his friends have quit coming. Our next door neighbor, she is just really great with him. She'll take him to movies, and his brother will occasionally come over and go bowling or do something like that. His biggest problem is communication. He understands, but people have a really hard time understanding him. I feel like I never have any time to myself. Since he did go back to work (part time), it gives me a few hours, at least 3 days a week, that I can do a few things on my own. I would say that's been the hardest for me. I need outside contact and socialization with people."

<u>Have a life of your own.</u> Some family members admitted they needed to get away from the situation, at times. One reported, "There were a couple of times when I just told our two kids, I've got to get out of here. You have to take over. I need a break...about two and a half weeks (laugh)!"

Another said, "Don't let yourself be tied down, you know, resume, in a sense, you need to get back into doing and having a life of your own. That's one thing I have failed to do, and I think that's made it even harder on me. So, you can get out and have time to yourself."

Provide service. Several suggested that it helped to provide service. In the words of one, "And then, serve others. It's kind of vague, but it really does help to get your mind off your own self." After agreeing, another said, "And allow (other) people to help. Church, non-church, family, I don't care. Let people help. They want to help. Don't decline, don't deny them the opportunity for service. I had somebody across the street who wanted to know if there was anything they could do. I said, no, really, you guys have been great. Obviously (they) wanted to do something. I said,, 'I'm having a hard time getting my clothes out of the cleaners. They've been there for a week and a half--not that I need them--I'm not wearing dress shirts and stuff. ..that would be helpful for me. So, the next morning, I left for the hospital at 6:00 AM. I took my old claim check and a \$20 bill and put it in an envelope and put it on the front door, not to wake them up. (When) I came home late that night, between 10:00 and 11:00, my laundry was in the house. and so was the \$20.00. I said, 'now, I didn't say you had to pay for my laundry.' They said, 'We know. but don't worry about it.' and that was a big thing to them. So, just let people help you more."

Others, who initially had a hard time dealing with their family member's accident gave advice. "I would advise you to stay in touch with reality, as much as you can, even as painful as it is." Another agreed: "I would try to tell the people involved that it's real. And, as a family member, they should look at it as being real. Have understanding and tolerance, and try to do what you can. And dealing with it. Maybe not solving it or curing it, but at least, dealing with it." Yet a third stated, "I think the greatest benefit is to talk about it with your family and keep the communication open. Don't be afraid to share your feelings."

A mother stated, "Be good to yourself. And not kick yourself if you should or if you shouldn't have, because, you know, you make mistakes as a parent, but you love your kid and try and do the best you can, everyday. Nobody is perfect. You know, we didn't have perfect parents, but we got through it."

Some family members experienced concern about how to help the patients after they returned home. One advised, "Don't baby them. I'm not saying not to be supportive, but let them try to get their strength back and do as much as they can for themselves, so that they can heal faster." Another addressed the mental aspect of recovery: "I'd probably let him take more responsibility. If he wants to sit on the couch all day long and look out the window, let him do it. Don't worry about it. Let him work it out himself."

One family member who felt she didn't fare well with hospital personnel admonished, "Ask more questions, ask a lot of questions. And get the answers. I asked questions and some of them, they wouldn't give them to me." However, she also suggested, "Look on the bright side, because there is a bright side to it. There always is." Several suggested things that would be helpful for them, at the hospital. One said, "There should be someone in the hospital or some kind of support service that comes to families and asks them if they need help. Another clarified, "If there was some type of information. I mean, they gave me pamphlets to read, but what does that tell you? It just tells you what could happen (to the patient), what has happened before. It doesn't say anything about what's going to happen to <u>you</u>. If there had been names of people that I could have called and said, 'this is what's happening, what did you go through?" Just have someone there to talk to for all those hours in the hospital. And to have somebody that said, 'This is my experience.' Then, as he got better, have different peoples' experiences, because everyone's different. When they don't get better, they might want to talk to someone like (family member whose husband did not improve). As they <u>do</u> get better, they might want to talk to someone like me." A mother agreed, emphatically; "When he was in the Rehab, it was more or less what he was doing. I'd watch them and all that. I'd watch the other parents, the husbands and wives do the same thing. But, there really wasn't nothing for the family, us. the parents, or whatever, to be involved in. We just sat back and watched our families work all that stuff. While they were doing their thing, we could be having therapy, too. Maybe we could consult with one another. Maybe we could share."

Another said, "I would look for support systems a lot sooner, a family type of support. You get support as soon as possible. But, we did the best that we knew how. The one thing that I would highly recommend is, don't be afraid to ask questions, and don't be afraid to get support from other people who have gone through it. It is something you don't want to deal with on your own

<u>Only one thing matters.</u> Regardless of the difficulties associated with the trauma experience, most family members felt it drew their families closer together. One said, "Our family was really supportive. Our (extended) families are closer together." Another emphatically declared, "There's only one thing that really matters, and that's your family. Nothing else matters. Material things don't matter. Your job? So what? You can get a different job. Nothing really matters, outside of your family."

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"We appreciate her a whole lot more. I've always loved my wife, and I have kind of a feeling about her now, even more than when I married her. Again, I don't know whether that's part of the accident, but I look back at that day when I saw that I almost lost my family..."

Several husbands felt the accident reinforced their marital relationship. One said, "It probably brought us closer together. She probably had to depend on me a little bit more. And it made us realize how much our neighbors and friends care about us. You find out who really cares about you."

Only one spouse discussed a decrease in sexual relations. He stated, "In fact, I'm starting to get a complex. She has really changed in that area. You start playing mind games, instead of being the mature adult that you're supposed to be on this issue. You're now thinking, well, she doesn't love me anymore. She's got some guy on the side, you know, whatever. You think stupid things, when it's really not that. It's just that she's changed, because of her injury." However, answers from the HDL-B indicated nearly half the family members had decreased pleasure in their sex life.

Support from others. Many family members discussed the help they received from others. One said, "To see how many friends you really have, when you really need people. Our ward, especially, and our families. Provided meals three days a week, parents had us over for dinners on Sundays, and we ate leftovers the other times. We got a lot of support from friends."

Another said, "His sisters were absolutely wonderful. I'm really close to my sister-in-law. It's like we're all one family. Good people. 'Cause I had the kind of job where I just couldn't take time off. They both were flexible enough that they could come over and stay with him, so there was somebody there."

Expressing surprise at all the help they received, one said, "It gave a lot of people the opportunity for service, a lot of people. In our old ward, in our new ward, in the stake, people we never even knew. I mean, we were getting meals from people I didn't know..."

Sometimes, the help from others was overwhelming. One said, "The support of our ward. They had special fasts and they did everything. I was a little proud, I guess. I slowly started to soften up. I learned a good lesson to be able to offer service to others, you've got to have somebody that is willing to help you. It's not weakness to let someone help you." <u>Family spiritual experiences.</u> Many family members had experiences they classified as spiritual. One said, "I don't know how to describe it--I knew she was going to be okay." Another said. "I probably received more spiritual witnesses of the reality of my God through that than I have in my whole life, because of a lot of fasting and a lot of prayer."

One, who lost a son and sister in his wife's accident, said, "Because of my belief, I know there is another side and I will see them, again. That helps out a lot...They know my feelings toward them... sometimes, you wish you could talk to them...those that have passed on. I still do... I still hope that something can happen. I tell my wife, 'okay, you made me a promise that if you die, you will come back and tell me that everything's okay' (laughing)."

Another advised, "Thank Heavenly Father the person is still alive. Be thankful she's not dead. You know, we had two wards fasting for us, our new ward here, and our old ward. If someone thinks fasting doesn't work and that the priesthood doesn't work, um, she's walking, living proof that it works." Agreeing, another reported, "There was a lot of prayer and things. We experienced a miracle, having her regain consciousness and recognize everyone and be able to talk. You know prayer and miracles do happen."

After discussing the struggle they experienced, one reported, "We leaned on each other-- instead of blaming one another--- and God to help us through. That was a big test of our faith and of our marriage." Another elaborated: "We're religious and I like to think I just don't go to my Lord just when I need him, but at times like that, if you didn't have that...it would have been really hard. There were times when the doctors would say, 'We've done all we can do. We don't know what else to do.' and if you didn't have your faith to turn to, that would be a really lonely, helpless feeling to just be sitting there...(tears) Well, let's just say, I knew the day she got hurt that she wasn't going to leave. There were times when my faith kind of weakened because of everything that was happening, and if I didn't have that witness that I had, (pause) the day of the accident to draw on, I'd have gone nuts. And there were times when we performed blessings on her... That would be the darkest hour, and when they were over, I knew she was going to be all right. I just know it was more than just medicine that got her through it." As a wife discussed the changes that are now occurring in her husband, she said, "Well, it's because of being spiritual and everything. My mom--after the accident--told me, 'I really feel like I am going to be the one to help him through this.' I didn't really think that much about it, and then...I don't know...A couple of years ago, she went for an angiogram and they found six blockages in her heart. So, she went in for a bypass surgery. About five days later, she had a stroke and was recovering from that, really well. About 2 months later, she collapsed and they couldn't get her heart started. She was on life support for a couple of days and then we turned it off. I had the opportunity to just kinda go in and talk to her for a little bit, right before we turned her machines off. (I) just had this overwhelming feeling of her saying, 'Now, I will be able to help him.' I just had that warm feeling and I know it sounds crazy. But, it's the only thing I can attribute it to, because ever since her death, things have gotten better with him.''

<u>Family quality of life.</u> Nearly all the family members agreed the quality of their lives had improved. Most of the family members who were interviewed were spouses to the major trauma patients. The spouses focused on marital relationships. One related, "We've always had a good marriage. If anything, it has improved, because of the traits that he's changed."

A husband stated, "I think my relationship with my wife is better than it's ever been. I appreciate her more. I'm more conscious of her needs, more aware of her. That part of the quality of my life, my marriage, is better. And I think our family is really unified. I think they (our children) really appreciate their parents, since they both got life flighted, at one time (or another). As far as quality of life, it's fine except for the recreation aspect. I miss it a lot."

Another husband, whose wife is unable to actively participate in athletic activities said, "We have diminished our quality of life, a little bit. But very little. I'm just grateful to still have my wife."

Another reflected, "As my relationship continues to grow with (my wife) and our two kids, it gets better and better. You always have that thought...you know...(the child who died) would be five years old right now, and you wonder how he would be. Playing with the kids right now, or would he be a hellion..you don't know. You have to wonder, would I be here in Utah or would I be somewhere else? But overall, the quality of our life has increased. I think the Lord has blessed us." There are some family members who did not agree that the quality of their lives had improved. One said, "I don't think the quality of our life has changed at all, in the sense that it hasn't impacted on our relationship, it hasn't impacted on our ability to earn an income. It hasn't impacted on our ability to take vacations, how we spend leisure time. It has made me more conscious, more cautious about a lot of things. But in terms of the overall quality of our life, he was lucky, we were both lucky, in the sense that it really did not alter things. I mean, he's lucky he didn't have brain damage. I mean the number of things that could have gone wrong are pretty frightening."

Another reported, "It has altered where we'll consider taking vacations for skiing. I mean, we were with a group of people, they talked about going to Europe, and we said, 'what? Are you crazy?' We only go to places that have formal, well established ski patrols, that aren't out of the way. That kind of thing."

A few feel the quality of their lives decreased, following the trauma. One, whose husband is one year post-trauma stated, "I don't think it will ever be the same as it was before. He tries and he doesn't realize it...he still forgets a lot of things. He can't do a lot of things like he did before, because he has no strength. He was a strong man. An iron worker, so he did a lot of things. Things are different. They're not going to be the same. But, we're happy with what we've got."

A mother, whose four year post-trauma son received both a brain injury and severe orthopedic injuries reported, "Home life is very straining. That has deteriorated. It just continues to get worse. It is his relationship with his dad. I'm just to a point, I just don't know what to do. I've been told that a trauma of this kind, or any trauma, really, can do an awful lot to a marriage, as well as a family. I can definitely see what it's done. Definitely a lot of stress. I ended up having a heart attack, and so it's been pretty rough. I don't know what else to do to bring it around. (But) just having him here, knowing he was dead when they arrived at the scene, it's all I can really ask for (crying). He is my baby, you know. We're just real, real close."

She continued, "I feel that we had a good life, before the accident. And since the accident, I have seen a deterioration of the quality of my life. We just don't do, go, or even really do anything much at all,

and it's all basically centered around him. I don't know if there are things that we could have done to ensure the quality of a family unit, or not. I would say, pretty close to 180 degree turn from the quality of life we were living before. You just have to have trust and peace within a family. In our case, that has been destroyed."

In despair, a mother of a one year post-trauma patient said, "Well, mine, as far as that goes. I never really did too much of any thing. I just go to church, and I still do that. I really don't do all that much more. I just work harder, that's all there is."

Tying quality of life back to lasting relationships, one summed it up with, "Quality to me is a harmonious relationship with family, peace with your Heavenly Father, doing what you should be, but knowing you've got that family relationship and that closeness to your Heavenly Father. Nothing temporal can really apply to quality of life."

#### Chapter 5

#### Discussion

Current trauma statistics show there are 60,000,000 injuries and 145,000 deaths a year, (American College of Surgeons Committee on Trauma [ACS], 1998). The NSC (1997) estimated that 20.1 million disabling injuries occur each year. The United States spends \$444.1 billion a year for acute trauma care. or 40% of health care costs. Trauma is the leading cause of death for 1 to 44 year olds and is third behind cancer and atherosclerosis for all age groups (ACS, 1998). Of head injuries suffered, 80% are mild (GCS > 12), but 3% of these will later deteriorate. Ten percent have moderate head injuries (GCS 9-12), and 20% of these will deteriorate. For the other 10% who have severe head injuries (GCS < 9), many develop such secondary sequelae as hypoxia (30%), hypotension (13%), or anemia (12%). If both hypoxia and hypotension are present, the mortality rate is 75% (ACS, 1998). Critical care nurses often express concern that patients and families are unaware of these grim statistics and the poor prognosis that often accompanies major trauma.

Major trauma occurs with no warning, leaving patients and families unable to make informed decisions before care begins. These circumstances give families few choices about strategies, even in the era of the Self Determination Act. Additionally, the nationwide move in the United States to control health care costs continues. Because major trauma uses such a large proportion of health care dollars, and because so little information is available about the long-term physical and psychosocial sequelae of trauma, this triangulated descriptive study was designed to examine the financial, physical, and psychosocial costs for major trauma care. Based on a cost classification matrix (see Figure 1), this study has provided cost data for each of those areas. It also identified costs for patients who died in the ED, those who died during acute care, and those who survived.

#### Financial Costs

This study bears out the high price paid for trauma care; the 370 major trauma patients reviewed here had total financial charges of \$9,945,973 and total institutional costs of \$7,089,962. LOS was closely related to financial charges and institutional costs (r = .89 and r = .91). Eighty-one patients (22%) died. with charges of \$1,269,217 and institutional costs of \$982,454. Of the eighty-one patients who died, 28 died in the ED with total financial charges of \$157,404 and institutional costs of \$164,439; fifty-three died during acute care with financial charges of \$1,111,813 and institutional costs of \$818,015 (see Figure 17). Of interest, for patients who died in the ED, the study facility chose to charge less than institutional costs.

One would expect financial charges for major trauma patients who died in the ED to be less than for those who died during acute care and this was confirmed by study results. Those who died in the ED died within one day, compared to those who died during acute care, who had an average LOS of 3.5 days. Survivors had longer LOS (mean 8.3 days) than those who died in the hospital.

Generally speaking, the most severely injured and the least severely injured major trauma patients, as measured by the GCS, RTS, and ISS, had lower financial charges than those who were moderately injured. Those severely injured patients who died soon after arrival did not utilize as many health care resources. Those who were not severely injured required longer observation, but used fewer costly interventions than those who survived with severe injuries. Higher financial costs are expected for those more severely injured who do not die, but require many more health care resources.

For those who survived, as outcome at discharge improved, financial charges declined. Patients who died and patients who had good recoveries had the shortest LOS (2.7 and 4.2 days, respectively) and, therefore, utilized fewer health care resources. Persistent vegetative state (PVS) patients had the longest mean LOS (24.7 days) and the highest mean financial charges (\$79,185). Those major trauma patients with moderate disabilities had 9.2 days LOS and mean financial charges of \$30,729. Those with severe disabilities had a mean LOS of 13.7 days, with mean financial charges of \$53,242. Of all the scoring systems, the GOS best equates injury with LOS and utilization of health care resources.

In summary, those who had minor injuries had lower financial charges. due to their shortened LOS and decreased utilization of health care resources, compared to those with moderate injuries. Clearly, those patients with major injuries were more likely to die early in treatment; therefore, they had lower financial charges. Those who had moderate injuries had the greatest LOS, required the greatest amount of health care resources and, subsequently, had higher financial charges. These findings suggest that it is imperative to identify the patients with major injuries who are likely to die, to examine current health care policies for their care, and to make changes where possible.

#### Pavers of Financial Charges

Earlier studies stated few major trauma patients had health insurance (Mackersie et al., 1995; Payne et al., 1993). In contrast, between 82 and 91% (exact percentage unknown, due to Medicare/Medicaid) of the major trauma patients in this study were covered by insurance.One-way ANOVA showed no significant differences (p = .441) in charges by payer group.

One cannot distinguish those who contributed to the Medicare/Medicaid fund from those who did not. Patients who receive Medicare may have paid in to the system; however, patients who receive Medicaid funding did not. Also, according to Merilee Petersen, financial agent from LDS Hospital (personal communication, September, 1997), the majority of "self pay" patients end up as charity patients. Even when combining Medicare/Medicaid, charity, self-pay, and crime victim compensation, there were no statistically significant differences (p = .649) between financial charges for those with commercial insurance and those without. These results suggest that the trauma center involved in this study serves a different patient mix than may be the case elsewhere.

#### Physical Function Costs

Obviously, the 81 patients who died paid the ultimate price in physical function costs. Previous studies indicated that 8 to 27% of major trauma patients die in the acute care setting and that mortality and morbidity rates are higher for those who are more severely injured (Gennarelli et al., 1994; Siegel et al.,

1994). This study confirms those findings, with a total of 22% who died, but it also separated those who died into two discrete categories---those who died in the ED (8%) and those who died during acute care (14%). Close scrutiny of the major trauma literature revealed no study that has delineated such information.

Survivors had many major injuries that were not life threatening, but required extended care. or, those with numerous complications had prolonged hospital stays. Major trauma patients who died in the hospital also had severe injuries and/or numerous complications. While computing relationships in this context, even after controlling for those who died in the ED, statistically significant differences still emerged between those who died in the hospital and those who survived. Survivors had better GCS scores (mean of 12.3 versus 5.6, p = <.001), better RTS scores (10.6 versus 6.2, p = <.001), and better ISS scores (19.7 versus 54.5, p = <.001).

Emhoff et al. (1991) found that 62% of their surviving trauma patients went to rehabilitation and 38% were discharged to their homes. Frutiger et al. (1991) reported that 2% were in PVS, 9% were severely disabled, and 89% had moderate injuries or good recovery. In contrast, using the GOS, this more extensive current study established that 22% of the major trauma patients died, 8% in the ED and 14% during acute care; 1% went to extended care facilities in PVS; 24% went to rehabilitation for severe injuries; and 52% were discharged to their homes with moderate injuries or good recovery.

The FIM is a functional assessment scale, primarily used in rehabilitation settings, for patients with multiple disabilities, although a modified FIM was used with patients from the national MTOS (Gennarelli et al., 1994). Subsequent studies would have benefitted if Gennarelli et al., (1994) had given the reason for using a modified version of the FIM in their trauma study. Had they provided their differences in criteria, other researchers could replicate their method. This researcher was unable to locate any major trauma patients who continued to have major deficits in physical function, as identified by the FIM, although three of the original major trauma patients were later classified as PVS, and eighty-two had severe disabilities at discharge from the acute care facility. All the patients evaluated in this study progressed, over time, following discharge and all were able to receive all the possible FIM points.

Recent literature (Hall, Mann, High, Wright, Kruetzer, & Wood, 1996) points out that the FIM has a "ceiling effect" that leaves it insensitive to changes in abilities, after patients return to the community. Patients from this study validated that position. Two of the patients used wheelchairs most of the time. one from the 3 to 4 years post-trauma group and one from the 2 years post-trauma group. Both could walk short distances, but neither performed at their former physical function level, even with their wheelchairs. Also, one of them communicated at a very elementary level, which prohibited pre-trauma function. Therefore, the FIM did not provide information about physical function that would differentiate major trauma patients into statistically significant categories based on physical function. These findings indicate the lack of utility of the FIM on follow-up studies of trauma outcomes among survivors. A new tool, the Functional Capacity Index (MacKenzie, Damiano, Miller, & Luchter, 1996) has been reported since the present study began and may overcome the limitations of the FIM in the community.

#### Patient Psychosocial Costs

One measure of psychosocial costs after major trauma was the HDL-B. When analyzing patients over time (6 months to 1 year, 2 years, 3 to 4 years, or 5 years post-trauma), no statistically significant differences emerged among the groups in any area except *Family Tasks* and *Partner Tasks*. Those who were at five years post-trauma reported accomplishing more family tasks (those the patient and someone else performed equally) than patients from any other group. Conversely, those who were at five years post-trauma credited partners with performing fewer partner tasks than did patients from the 6 months to 1 year group. Study findings suggest that since patients in the five years post-trauma group had better outcomes at discharge than other cohorts (mean GOS 4.27, compared to GOS 3.55, GOS 3.66, and GOS 4.0, p = .0078), the differences noted and the HDL-B results may be a function of better status at discharge rather than improvement in function over time.

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#### Respondents versus Nonrespondents

When comparing respondents who answered the survey questions to nonrespondents, several differences were noted. Although the RTS scores for respondents were statistically lower (10.06 compared to 10.84, p = .0399), such small differences were not clinically significant. The respondents had lower financial costs than the nonrespondents and more of their financial charges were paid by commercial insurance or workmen's compensation. The respondents received no Medicare/Medicaid, self-pay, active duty military, or crime victim compensation.

As to probable causes for non response, patients in the military could be expected to move and be lost to this study, but some of the patients covered by other forms of insurance should have been traceable. Many have moved, leaving no forwarding address or the forward has run out. Telephone books, operator assistance, and follow-up on forwarding addresses failed to find them in the local area or at their residence listed at the time of the accident. While gathering the data, the researcher noted that some patients obviously had no permanent address (eg., the hospital or the 400 South viaduct were listed as the permanent address). Perhaps those patients who self-paid, which frequently means charity, were less stable members of the community. The same may be true of the Medicaid population. Those patients would be among the two hundred two whom the researcher could not contact.

This disparity prevents this study from correctly identifying the psychosocial costs for all participants and reflects a serious limitation to this study. Similarly, other studies contain gaps denoting differences in those interviewed or surveyed and those who were not (Holbrook et al., 1994, Landsman et al., 1990; Strohmyer et al., 1993). Results from the current survey and interviews cannot be generalized to the general trauma patient population; nor can the data about their families be generalized beyond the present study.

#### Family Psychosocial Costs

Family members also completed the HDL-B as a measure of psychosocial cost. As reported in the results section, family members at 3 to 4 years post-trauma had more depressive feelings than family

members at 5 years post-trauma and even at 6 months to 1 year post-trauma. Possibly, those who were 5 years post-trauma had resolved personal issues surrounding the trauma and, therefore, retained fewer depressive feelings. Also, the patients who were 5 years post-trauma had better mean GOS scores (4.7 versus 3.5 for 3 to 4 years post-trauma) at discharge, so the families may not have gone through as many negative experiences as a source of depressive feelings. Family members at only 6 months to 1 year post-trauma might still be dealing with the physical aftermath and relief at the patient's survival. Introspection leading to depressive feelings could lie ahead.

Family members at 5 years and 3 to 4 years post-trauma have fewer single events (moved to a new residence, had a greatly increased workload; your child left home; a child or other relative moved into household; alcohol or drug problem; your own serious illness or injury; serious illness or injury of a family member) in the previous 3 months, 6 months, and 12 months than family members at 2 years post-trauma, which suggests that their situation became more settled. However, family members at 5 years and 3 to 4 years post-trauma had the most negative events (lost something of sentimental value; death of a close friend; trouble with friends or neighbors; separation; divorce; trouble with in-laws; death of a spouse: death of an immediate family member other than a spouse; trouble with superiors at work; laid off or fired from a job. unemployed for a month or more; income decreased substantially; went deeply into debt; legal problems; assaulted or robbed) in the preceding year than family members at 2 years post-trauma. In reviewing the indices included in single events and negative events, one finds the single events are of a positive nature (eg. engagement, birth of a child, took a better job), while the negative events are not (eg, divorce, death of a close friend, trouble with in-laws, laid off or fired from a job, went deeply into debt). Perhaps there is no disparity.

## Trauma Patients and Families Compared to Community Members

Although there may be no statistical significance in certain differences among patients, families, and community members, as portrayed by the HDL-B, some clinically significant differences were notable. During the qualitative interviews, patients and families shared some of the changes they experienced as a

result of the trauma. Several discussed depressive aspects with which they dealt-having no desire to go out of the house, being too tired to get up and get dressed, secluding themselves from the public because of their looks or feelings. Several mentioned taking antidepressants. Additionally, patients and families reported much higher rates of visits to mental health professionals than did community members, with patients having the highest numbers of visits.

Although patients and families reported slightly higher medication use than community members. they consumed considerably less alcohol, with less frequency, and had fewer drinking or smoking problems, possibly because of their religious affiliation, which discourages such practices. Another possible explanation could be that nearly all of the major trauma patients and their family members were much more appreciative of significant others since the trauma. They placed more value on their families than before and had an increased awareness and respect for life. Differences noted between study participants and the general public suggest that trauma patients and their families experience more depression and need more mental health care, but have a heightened appreciation for significant others.

#### Quality of Life for Patients and Families Post-Trauma

Although some post-trauma patients discussed present limitations, such as minor physical disabilities, temporary financial setbacks, poor memory, and inability to concentrate, all but one believed the quality of their lives had improved. Their appreciation for life, family, friends, and neighbors had grown. Some went so far as to call the trauma a gift, or a blessing, and related accompanying spiritual experiences.

Many family members discussed their initial fear that their traumatized relative would die and that they were at the mercy of health care providers. They related how hard it was for them at the hospital and then, again, after the patient went home. Many expressed regret for the part of their lives that is gone, for the limited physical abilities of the post-trauma patient.

They expressed being angry at some point--at the person responsible for the accident, at God, and at their losses. However, after voicing the negative aspects of their trauma experience, with but two exceptions, all the family members stated the quality of their lives had improved. Their families had drawn closer together; spouses reported improved marital relationships and mothers became closer to their sons. Of those who appreciated life more, many feel a Spiritual Power had helped. Comments by both patients and family members regarding their quality of life suggest that regardless of the negative experiences that accompanied their trauma, the quality of their lives had improved.

#### Discussion Summary

Several measures contrast with conditions cited in former studies. First, 81 to 92% of the major trauma patients in the present study had insurance coverage. Second, nearly all of the patients and family members who were interviewed reported the quality of their lives had increased post-trauma due to their increased appreciation for each other, or other family members, and for friends. Third, 87% of the study population was Caucasian. Fourth, contrary to MacKenzie et al.'s study (1990) where 12% of the trauma patients were more than 65 years of age and accounted for 25% of the charges, the current study found only 1% were more than 65 years of age and accounted for .02% of the charges. Similar to Bennet et al.'s findings (1989), four of the five who were more than 65 years of age died; one in the ED; three in acute care on the first day.

Surprisingly, there were virtually no differences in perceptions of quality of life for HDL-B or interviewed patients for any of the time periods from 1991 to 1996. Like Condeluci et al.'s results (1992), the qualitative portion of the present study found that the psychosocial adaptation of post trauma victims was negatively affected by episodes of agitation, irritability, and poor interpersonal relations. These problems were compounded by poor memory and inability to concentrate, in agreement with Gensemer et al. (1988). By self report and family member report, six of the twenty patients who were interviewed continued to have difficulty with interpersonal interactions. They forgot things; they could not concentrate fully; they were easily distracted, and they became irritable with little provocation. One continued to communicate at an elementary level. Yet, one returned to full employment after five years, just shortly before being interviewed. Four worked part-time, and one quit working at the time of the interview, because of difficulties with social interactions.

One former major trauma patient had to file bankruptcy, after being unable to pay mounting medical and daily living expenses. One former patient is serving a jail sentence, related to the accident. In contrast to an earlier study (Hall, et al., 1994) in which nearly half of the family caregivers relinquished employment to care for a post trauma patient, in this study, only one person, a mother, quit her job to care for her son.

Many family members stated how difficult it was to deal with the unexpected emotional changes exhibited by the patients. Three family members declared their inadequacy to continue providing care and living with the patient.

Even with the exceptions listed above, former trauma patients and family members overall declared emphatically that the accident was a positive experience for them. Their appreciation of each other, friends, and neighbors grew as did appreciation of life. Clearly, those patients and family members who were interviewed felt their trauma care was worth whatever it cost, financially, physically, and psychosocially.

#### **Limitations**

Although financial costs for professional fees and for rehabilitation are significant, information about these costs was not collected or examined in this study. Gathering these data would have required access to the financial records of many health care providers and was beyond the scope of this research.

The majority of the patients in this study were Caucasian, as were all of the patients and family members who were interviewed, with one exception. As most trauma centers serve a more diverse population, cultural differences may influence the results and prevent generalizing these results.

Since the patients in the study were transported by helicopter, the economic data shown cannot be generalized to major trauma patients transported by fixed-wing aircraft or by ground ambulance. The FIM's lack of sensitivity to changes in physical function for those patients who were discharged home limited the value of such information. Owing to the sensitive nature of trauma experiences, family members of patients who died, either in the Emergency Department or during acute care were not contacted. However, they would have added rich perspective to the body of research on psychosocial costs of major trauma. Family members for the patients who died may report different feelings. For the 28 patients who died in the ED, families had no opportunity to make choices. Additionally, for those 53 who died during acute care, families may have wished to forego the roller coaster emotional experiences.

#### Recommendations for Further Research

A prospective study of trauma patients similar to that described here would enable a researcher to contact patients and family members while they were still in acute care, experiencing the first aftermath of trauma. Such a study would facilitate follow-up, and could include family members of patients who die. Such a study would require great sensitivity, but could provide deeper, richer insight into the psychosocial experiences patients and families face.

A prospective study that focuses on financial, physical, and psychosocial costs in a trauma center is needed. It would facilitate access to participants after they return to the community. Additional follow-up would include patients in rehabilitation centers or extended care facilities. In conducting such a study, the researcher would have access to most or all the financial expenses incurred in a variety of settings, beyond the cost categories addressed in this study.

This study evaluated data only for major trauma patients who were transported by helicopter directly from the scene to a Level I Trauma Center. These data should be extended to include major trauma patients who are transported by other means and to other facilities.

The results of the HDL-B and qualitative interviews from this study suggest that a longitudinal study to examine differences in outcomes for trauma patients may be unnecessary. In this study, patients' physical functions and psychosocial function for them and their family members changed very little over time.

#### Recommendations for Practice

Though other studies reported many trauma patients had no insurance, the majority of the patients in this study had commercial insurance or compensation through their employment. Also, the financial charges for trauma care in this study were higher than the costs to the institution. This information should alleviate any concerns this trauma center may have about financial viability. However, the trauma facility in this study did lose money on patients who died in the ED with both a GCS of 3 and an RTS of 0. Ninetythree percent of the major trauma patients who had both a GCS score of 3 and an RTS score of 0 died, with financial charges of \$117,548 and institutional costs of \$129,984. These results are similar to those discussed by Pasquale et al. (1996) and Quigley et al. (1997). From a financial cost-effectiveness perspective, it may be in society's best interest to pronounce all such patients dead in the field, as Pasquale et al. suggested. Or, as Quigley et al. stated, "if confirmed at other centers, this may have wide-ranging implications regarding counseling of families [and] utilization of resources..." (p. 7). Eliminating the monetary expenditures for such patients would enable health care providers to divert health care resources to more appropriate care for other patients.

The counseling of families suggested by Quigley et al. (1997) could also prevent some of the prolonged pyschosocial costs for family members who are experiencing fear, anxiety, and anguish, as they hopefully wait for positive outcomes in a negative situation. In the qualitative interviews, family members repeatedly reported the fear and uncertainty they experienced as they waited in the hospital. From a psychosocial cost-effectiveness perspective, eliminating days or weeks of needless distress for family members, when the patient would die anyhow, certainly would be appropriate.

Patients and family members also recommended that support groups would be beneficial, both in the hospital for families and post-discharge for both patients and families. They suggested that such groups would help them identify outside resources (others who had similar experiences and health care providers to help them work through their feelings) to put things into perspective.

In the future, regardless of decisions about providing care to severely injured patients, nurses can assist family members in their psychosocial experiences. Following the suggestions of families in this

study, nurses could arrange more support for families while they are still at the acute care facility. They could also arrange follow-up home visits or telephone calls to ensure that families are receiving appropriate help.

Perhaps the most important recommendation to come from this study is to share patients' and families' perspectives. Educators could provide information to nurses to alleviate concerns about the quality of life for major trauma patients and their family members. Based on this study, patients and families can be encouraged to feel that the quality of their lives can improve, as they learn to appreciate each other and their community support systems, even in the face of physical limitations.

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#### Appendix C UNIVERSITY of SAN DIEGO and LDS HOSPITAL CONSENT FOR PARTICIPATION IN AN INVESTIGATIONAL STUDY Consent for Patient Major Trauma Outcomes: At What Cost? And For Whom?

#### GENERAL INFORMATION

You are being asked to participate in a research study which will analyze current health and quality of life for former major trauma patients and their families. Your health will be evaluated through a self-reported questionnaire that will take you about an hour to complete.

Additionally, you may be asked to participate in an assessment of your physical abilities and an interview. If you are asked for the assessment and interview, they will take about one and a half hours of your time. Participation in the study will not involve any anticipated risks or discomforts, except possible minor fatigue. There are no anticipated benefits, but an indirect benefit may come as you discuss you feelings about being a major trauma patient. Future patients and families may benefit from your experience. For questions concerning the research and your rights as a subject, contact <u>Elaine Bond at (801) 378-4891</u>. If necessary, further information can be obtained from Kendell Nelson, Assistant to the Administrator, 801-321-1968.

#### DESCRIPTION OF SPONSORING/GRANTING AGENCY

This research study is being conducted by Elaine Bond for her doctoral degree in nursing at the University of San Diego. Neither the University of San Diego nor LDS Hospital provides any separate funds for the support of the investigator or conduct of this research study.

#### FINANCIAL DISCLOSURE

There are no expenses for participation in this study. Elaine Bond will provide a postage-paid envelope for participants to return the questionnaire. If you are selected for the assessment and interview, she will travel to your residence or a place nearby that you choose.

#### CONSENT.

I understand that participation in this study is voluntary and that my refusal to participate will involve no penalty or loss of benefits to which I would otherwise be entitled and that I may discontinue participation at any time without penalty or loss of benefits to which I would otherwise be entitled.

I understand that my participation in this study may be terminated by the investigator without regard to my consent under the following circumstances: If I refuse to continue with the assessment or interview. I understand that if I decide to withdraw from this study, arrangements will be made for an orderly termination.

Records will be held in confidence by the investigator, the sponsor of the research, and the Institutional Review Board. They may be inspected by the Food and Drug Administration. Any release of information derived from these records to scientific organizations, medical journals, nursing journals, etc. will be done only without identification of the subjects.

I have read the foregoing and my questions have been answered. I desire to participate in this study and accept the benefits and risks. I give permission for information gathered in this study to be released to LDS Hospital. I, the undersigned, understand the above explanations and, on that basis, I give consent to my voluntary participation in this research.

| Date              | Signature of Subject  |
|-------------------|---|
| Date              | Witness   |
| If the subject is | unable to consent, please fill out the following:   |
|                   | ation of the possible benefits and risks as outlined, I approve participation of (subject's name) |
| Date              | Signature   |
| Relationship to   | Subject   |
| Date              | Witness   |
| Date              | Researcher  |

#### Appendix D

#### UNIVERSITY OF SAN DIEGO and LDS HOSPITAL CONSENT FOR PARTICIPATION IN AN INVESTIGATIONAL STUDY Consent for Family Member or Significant Other Major Trauma Outcomes: At What Cost? And For Whom?

#### GENERAL INFORMATION

You are being asked to participate in a research study which will analyze current health and quality of life for former major trauma patients and their families. Your health will be evaluated through a self-reported questionnaire that will take you about an hour to complete.

Additionally, you may be asked to participate in and an interview. If you are asked for the interview, it will take about one hour of your time. Participation in the study will not involve any anticipated risks or discomforts, except possible minor fatigue. There are no anticipated benefits, but an indirect benefit may come as you discuss you feelings about being a family member or significant other to a major trauma patient. Future patients and families may benefit from your experience. For questions concerning the research and your rights as a subject, contact <u>Elaine Bond at (801) 378-4891</u>. If necessary, further information can be obtained from Kendell Nelson, Assistant to the Administrator, 801-321-1968.

#### DESCRIPTION OF SPONSORING/GRANTING AGENCY

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#### FINANCIAL DISCLOSURE

There are no expenses for participation in this study. Elaine Bond will provide a postage-paid envelope for participants to return the questionnaire. If you are selected for the assessment and interview, she will travel to your residence or a place nearby that you choose.

#### CONSENT.

I understand that participation in this study is voluntary and that my refusal to participate will involve no penalty or loss of benefits to which I would otherwise be entitled and that I may discontinue participation at any time without penalty or loss of benefits to which I would otherwise be entitled.

I understand that my participation in this study may be terminated by the investigator without regard to my consent under the following circumstances: If I refuse to continue with the interview. I understand that if I decide to withdraw from this study, arrangements will be made for an orderly termination.

Records will be held in confidence by the investigator, the sponsor of the research, and the Institutional Review Board. They may be inspected by the Food and Drug Administration. Any release of information derived from these records to scientific organizations, medical journals, nursing journals, etc. will be done only without identification of the subjects.

I have read the foregoing and my questions have been answered. I desire to participate in this study and accept the benefits and risks. I give permission for information gathered in this study to be released to LDS Hospital. I, the undersigned, understand the above explanations and, on that basis, I give consent to my voluntary participation in this research.

| Date | Signature of Subject |  |
|------|----------------------|--|
| Date | Witness              |  |
| Date | Researcher           |  |

| Α. | Eve opening:            | C. | Motor response:                        |   |
|----|-------------------------|----|--|---|
|    | Spontaneous             | 4  | Obeys commands                         | 6 |
|    | To voice                | 3  | Localizes pain                         | 5 |
|    | To pain                 | 2  | Withdrawal from pain                   | 4 |
|    | None                    | 1  | Flexion from pain                      | 3 |
|    |                         |    | Extension from pain                    | 2 |
| B. | Verbal response:        |    | None                                   | 1 |
|    | Oriented                | 5  |  |   |
|    | Confused                | 4  | Points range from 3 to 15 with 3 being |   |
|    | Inappropriate words     | 3  | the worst.                             |   |
|    | Incomprehensible sounds | 2  |  |   |
|    | None                    | 1  | GCS = A + B + C                        |   |

Glasgow Coma Score (GCS)

-

## Appendix F

| Α            | B                    | С                     |       |
|--------------|----------------------|-----------------------|-------|
| Glasgow Coma | Systolic Blood       | Respiratory           | Coded |
| Score        | Pressure             | Rate                  | Value |
| 13-15        | > 89                 | 10-29                 | 4     |
| 9-12         | 76-89                | > 29                  | 3     |
| 6-8          | 50-75                | 6-9                   | 2     |
| 4-5          | 1-49                 | 1-5                   | 1     |
| 3            | 0                    | 0                     | 0     |
|              | Scored from 0 to 12. | The worst score is 0. |       |

Revised Trauma Score (RTS)

-

## Appendix G

## Injury Severity Score (ISS)

| FaceMouth, eyes, nose and facial bones.ChestAll lesions to internal organs. Also diaphragm, rib cage, and thoracic sp  | ne. |  |  |  |  |
|--|-----|--|--|--|--|
| Abdomen/Pelvis All lesions to internal organs. Also lumbar spine.  |     |  |  |  |  |
| Extremities Includes shoulder girdle. All amputations, pelvic girdle fractures, dislocations and sprains, except for the spinal column, skull and rib cage.  |     |  |  |  |  |
| External Lacerations, contusions, abrasions, and burns, independent of their locati<br>on the body surface.  | n   |  |  |  |  |
|  |     |  |  |  |  |
| AIS <u>Severity Code</u>   |     |  |  |  |  |
| 1 Minor  |     |  |  |  |  |
| 2 Moderate<br>3 Serious  |     |  |  |  |  |
| 3 Serious  |     |  |  |  |  |
| 4 Severe   |     |  |  |  |  |
| 5 Critical   |     |  |  |  |  |
| 6 Maximum injury virtually unsurvivable  |     |  |  |  |  |
| An ISS of 75 is the worst possible score. Injuries coded AIS-6 are automatically assigned as ISS of 75. To figure the ISS, sum the squares of the highest AIS grades from the three most severely injured areas. |     |  |  |  |  |
| ISS = A  squared + B  squared + C  squared   |     |  |  |  |  |

Note: Adapted from Committee on Injury Scaling (1985).

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## Appendix H

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#### Glasgow Outcome Scale

|    | Score/Category                                    | Definition   |  |  |  |  |
|----|---|--|--|--|--|--|
| 1. | Death   |  |  |  |  |  |
| 2. | Persistent Vegetative State                       | Patient remains unresponsive and speechless for an<br>extended period of time. May open eyes and show<br>sleep/wake cycles, but shows an absence of function in<br>the cerebral cortex as judged behaviorally.   |  |  |  |  |
| 3. | Severe disability<br>(conscious but disabled)     | Dependent for daily support by reason of mental or<br>physical disability, usually a combination of both.<br>Severe mental disability may occasionally justify this<br>classification in a patient with little or no physical<br>disability.   |  |  |  |  |
| 4. | Moderate disability<br>(disabled but independent) | Can travel by public transport and work in a sheltered<br>environment and can therefore be independent insofar<br>as daily life is concerned.<br>The disabilities found include varying degrees of<br>dysphasia, hemiparesis, or ataxia, as well as<br>intellectual and memory deficits and personality<br>change. Independence is greater than simple ability to<br>maintain self-care within the patient's home. |  |  |  |  |
| 5. | Good recovery                                     | Resumption of normal life even though there may be a minor neurologic and pathologic deficits.   |  |  |  |  |

•

|   | tional inde | F   |     |     | <u>,</u> | ·   |     |     |
|---|-------------|-----|-----|-----|----------|-----|-----|-----|
| Observation<br>SELF-CARE Dates              | GOAL        | FIM | FIM | FIM | FIM      | FIM | FIM | FIM |
| A. Eating                                   |             |     |     |     |          |     |     |     |
| B. Grooming                                 |             |     |     |     |          |     |     |     |
| C. Bathing                                  |             |     |     |     |          |     |     |     |
| D. Dressing-upper body                      |             |     |     |     |          |     |     |     |
| E. Dressing-lower body                      |             |     |     |     |          |     |     |     |
| F. Toileting                                |             |     |     |     |          |     |     |     |
| SPHINCTER CONTROL<br>G. Bladder Management  |             |     |     |     |          |     |     |     |
| H. Bowel Management                         |             |     |     |     |          |     |     |     |
| MOBILITY<br>I. Bed, Chair, W/Chair Transfer |             |     |     |     |          |     |     |     |
| J. Toilet Transfer                          |             |     |     |     |          |     |     |     |
| K. Tub, Shower Transfer                     |             |     |     |     |          |     |     |     |
| LOCOMOTION<br>L. Walk/W Chair               |             |     |     |     |          |     |     |     |
| M. Stairs                                   |             |     |     |     |          |     |     |     |
| COMMUNICATION<br>N. Comprehension           |             |     |     |     |          |     |     |     |
| O. Expression                               |             |     |     |     |          |     |     |     |
| SOCIAL COGNITION<br>P. Social Interaction   |             |     |     |     |          |     |     |     |
| Q. Problem Solving                          |             |     |     |     |          |     |     |     |
| R. Memory                                   |             |     |     |     |          |     |     |     |

Appendix I Functional Independence Measure (FIM)

Weekly chart for each of 18 functional areas. Scores (1-7) are assigned for each task and totaled for each of six areas

#### **Complete dependence**

#### **Scoring Scale**

 $1 = \text{Total assistance needed (subject = <math>0\% +$ )} 2 = Maximum assistance (subject = 25% +)Helper Modified dependence

- 3 = Moderate assistance (subject = 50% +)
- 4 = Minimal assistance (subject = 75% +)
- 5 =Supervision

## No helper

6 = Modified independence (device necessary) 7 = Complete independence (timely, safely)

#### Appendix J

## Health and Daily Living Adult Form B [HDL-B]

The copyrighted HDL-B instrument (Moos et al., 1990) can be administered as a questionnaire or an interview. It examines personal and environmental life stressors. and the social resources and coping skills that influence adaptation. Its 260 questions are divided into seven subscales, which can be used independently: health-related functioning, social functioning and resources, family functioning and home environment, children's health and functioning, life change events, coping responses, and family level composite. It has four- and five-point Likert scale questions, yes/no questions, and open-ended questions. Cronbach's alpha was not reported for indices (16 out of 44) which had fewer than four items or when "the statistic was not considered appropriate, such as a count of essentially independent conditions: (p.4). Alpha coefficients ranged from .48 for *Number of Social Contacts* to .92 for *Global Depression*.

## HEALTH AND DAILY LIVING FORM Test Booklet: Adult Form B

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## Appendix K

### Grounded Theory Questions

Using a grounded theory and field research design, the following general questions will be asked of the participants: (a) Tell me what it has been like to be [to care for] a trauma patient? (b) If you had it to do over, what would you have done differently? (c) What positive things have you experienced? (d) What negative things have you experienced? (e) Tell me about the financial impact this experience has had for you. (f) What would be your advice to others in a similar circumstance? (g) After showing the patient/significant other the researcher's definition of Quality of Life (Bond, 1996), the last question will be asked--How would you describe your quality of life pre-trauma and post-trauma? The researcher will use these initial probes for unstructured interviews to determine patient/family perceptions of the psychosocial costs of trauma. The investigator will allow the participants to steer the interviews to events that are meaningful to them.