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**Self-Reported Health, Life Satisfaction, and Illness Intrusiveness
in Trauma Survivors**

by

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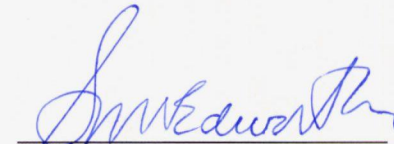
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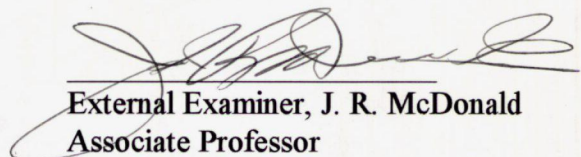
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ABSTRACT

This study describes the life satisfaction (LS) and self-reported health status (HS) of adult trauma survivors (excluding severe head and spinal cord injured and rural residing individuals) entered into the Trauma Registry of the Calgary General and Foothills Hospitals from April 1, 1993 to March 31, 1994. There were 49 participants (63.6% response rate) who were approximately one to two years post injury.

The LS ratings were slightly higher, and HS ratings slightly below, the general population. The primary referents for LS and HS demonstrated considerable overlap, but differed in frequency with which they were reported. The categories of referents were consistent with the domains identified as most important through the Illness Intrusiveness Scale and the Sickness Impact Profile. Although long-term effects of injury have the greatest impact on psychosocial functioning, physical functioning remains a concern. LS, HS, Illness Intrusiveness, and sickness impact were all associated.

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DEDICATION

To my husband Sean... my support, my son Seamus... my motivation, and my family

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CHAPTER 1

INTRODUCTION

Injury constitutes a significant public health problem and is described as the unsolved epidemic of modern society (Baker, O'Neill, Ginsburg, & Li, 1992; Davis, 1991; Jaffin, Champion, & Boulanger, 1993). It is a multisystem disease, and therefore benefits from almost any advance in medical science (Davis, 1991). Trauma is a leading cause of death in young adults, and severely injured trauma patients often require intensive care management (Frutiger, Ryf, Bilat, Rosso, Furrer, Cantieni, et al., 1991). With improvements in acute care management of trauma victims however, survival rates have increased (Frutiger, et al., 1991; Holbrook, Hoyt, Anderson, Hollingsworth-Fridlund, & Shackford, 1994; Jaffin, et al., 1993; Strohmyer, Noroian, Patterson, & Carlin, 1993). Due to this trend toward increasing survival rates, it is important to explore both short and long term outcomes of trauma (Holbrook, et al., 1994). Trauma survivors can expect minimal decreases in life expectancy, however, little is known regarding other long-term outcomes of this population (i.e., degree of disability, psychological well-being, satisfaction with life, etc.) (Frutiger, et al., 1991; Holbrook, et al., 1994; Mata, Fernandez, Carmona, Delgado-Rodriguez, Ruiz, Pugnaire, et al., 1992; Ridley & Wallace, 1990).

It is extremely important to explore quality of life and related outcomes (i.e., life satisfaction (LS), self-reported health) in this population in order to understand their long-term outcomes. Subsequent sections will address the current state of knowledge with respect to characteristics of the trauma population, factors associated with post trauma outcomes, the main categories of post-trauma outcomes, and self-rated health status (HS). The following review of the literature will identify gaps in the current state of knowledge which led to the development of this study.

SELECTED LITERATURE REVIEW

Background

Definition of Trauma

Trauma, or injury, is caused by exposure to physical agents such as mechanical energy, heat, electricity, or chemical and ionizing radiation which interact with the body in amounts or at rates that are beyond the body's resilience. The amount of energy that exceeds body tolerance and host susceptibility determine the severity of injury. Injury is a word seen in the non clinical, public health literature, whereas trauma is the word used to describe bodily damage in clinical, emergency medical services, surgical, and combat environments. These words are used interchangeably in the literature and will also be used interchangeably in the following discussion (Baker, et al., 1992; Jacobs & Jacobs, 1991; Robertson, 1992).

Characteristics of the Trauma Population

Trauma has been identified as the leading cause of death and disability in people under the age of 44 years and the fourth leading cause of death for all ages (Baker, et al., 1992; Champion, Copes, Sacco, Lawnick, Keast, Bain, et al., 1990; Jaffin, et al., 1993; Strohmyer, et al., 1993). The typical trauma victim is a younger male, with the highest injury rate occurring in 15 to 24 year old men because of exposure to high-risk activities (Weigelt & McCormack, 1994). The risk for males is 2.5 times that of females (Weigelt & McCormack, 1994). Despite decreases in the proportion of deaths due to injury as age increases, the death rate from injury is actually higher among the elderly than among young people (Baker, et al., 1992). Therefore, in absolute numbers, injury remains important throughout life.

The occurrence of injury is largely determined by characteristics of the environment and the many products we use through our employment, recreation, and travel (Baker, et al., 1992). The incidence and severity of injury are influenced by

demographic factors such as age, sex, race and occupation as well as by economic, temporal and geographic effects (Baker, et al., 1992). In all countries, the leading source of injury is by far mechanical energy (3/4 of all injuries), with the biggest single contribution in relation to mechanism of injury being made by motor vehicle accidents (Baker, et al., 1992; Robertson & Redmond, 1991; Robertson, 1992).

The Major Trauma Outcome Study of trauma victims throughout Canada, United States, Australia, and the United Kingdom is the largest existing descriptive data-base of injured patients (Champion, et al., 1990). Motor vehicle injuries accounted for 49.1% of the trauma victims in this study. Intentional injury, gunshot, and stabbing accounted for 19.5%, and falls caused 16.5% of the traumas. Three quarters of the victims were male. Most patients were between 15 and 55 years old (Champion, et al., 1990). The overall mortality rate was 9% (Champion, et al., 1990). Patients with gunshot wounds had the highest mortality rate (20.9%) and injured pedestrians had the second highest (13.6%), and the longest stays in hospital and most intensive care unit (ICU) days.

The Alberta Data Report on Injury Deaths and Hospitalizations reported a decrease in rates of death from 60.68 per 100,000 in 1986 to 52.89 per 100,000 in 1990 (Injury Data Coordinator, 1993). The most frequent cause of death was motor vehicle collisions (33% of injury deaths) followed by suicide or self inflicted injuries (27%). The most common cause of hospitalization was falls (33%) followed by motor vehicle collisions (16%). From 1985-1990 approximately 2.5 times as many males (6,180) as females (2,440) died from injury related incidents. Males accounted for approximately 60% of injury hospitalizations during the same time period, with the hospitalization rate for both males and females showing a decreasing trend. Over half of the total injury deaths and half of the hospitalizations were individuals between the ages of 15 and 44.

Data from the Annual Report to the Alberta Provincial Advisory Committee on Trauma Services (unpublished) includes trauma statistics from April 1, 1993 to March 31, 1994. During this time period, 59% of total injuries occurred in individuals aged 15-44.

Again, motor vehicle collisions accounted for the most injuries (42%) and the most deaths from injury (38%), with falls second (25% of all injuries and 22% of all deaths). There was a mortality rate of 14.4%, and 59 % of all trauma victims were discharged home. Fifty-six percent of the injuries occurred in rural areas.

Factors Determining Outcome

Many factors have been suggested as determinants of outcome in trauma patients including external factors such as injury severity, time until definitive care, and the quality of care delivered, as well as host factors which include age, gender, and pre-injury HS.

Severity of illness has been demonstrated to be a significant predictor of mortality after an ICU admission among both trauma and non trauma patients (Kass, Castriotta, & Malakoff, 1992). The Injury Severity Score (ISS) and the Revised Trauma Score (RTS) are two measures of injury severity that are used for triage and outcome (mortality) prediction. The ISS is a measure of anatomic injury, which is calculated by summing the squares of the highest Abbreviated Injury Scale (AIS) grade in each of the three most severely injured body regions. AIS scores are integers from 1 to 6 (1 or 2 being minor, 3, 4, and 5 increasingly severe, and 6 represents injuries considered to be incompatible with life). The ISS takes on integer values from 1 to 75. Patients with an AIS score of 6 in any body region are automatically assigned the maximum score (Copes, Champion, Sacco, Lawnick, Keast, & Bain, 1988). The Trauma Score (TS) is a physiologic severity of injury score which numerically summarizes assessments of circulatory, respiratory, and central nervous system function. The RTS was developed in response to concerns that the TS underestimates the severity of head-injured patients and is difficult to implement at injury scenes (based on capillary refill and respiratory expansion). The RTS is based on the Glasgow Coma Scale (GCS), systolic blood pressure, and respiratory rate (values of 0-4 assigned for each system for a total score of 0-12) (Champion, Sacco, Copes, Gann, Gennarelli, & Flanagan, 1989). The ISS and RTS do not explain more than 50% of the

variance seen in mortality, and therefore, must be used in conjunction with clinical assessment (Rutledge, Fakhry, Rutherford, Muakkassa, & Meyer, 1993).

Current severity of illness indices focus solely on mortality, assessing severity of illness based on the probability of dying (Schuster, 1992; Suter, Armaganidis, Beaufils, Bonfill, Burchardi, Cook, et al., 1994). Therefore, they are unlikely to be valid tools for predicting other outcome variables such as QOL or LS (Schuster, 1992).

An increased likelihood of mortality has been associated with the severity of pre-existing disease as well as with the number of pre-existing diseases, and the effect is most pronounced on those trauma victims less than 55 years of age (Milzman, Hinson, & Magnant, 1993). Although pre-existing disease has been associated with poorer outcomes (mortality), the prevalence of pre-existing disease in the trauma population is quite low (14-16%) compared to non trauma populations, as trauma victims are younger and healthier than those in non trauma populations (Frutiger, et al., 1991; Milzman, et al., 1993). It also appears that no single factor in the patient's physiologic reserve can truly predict survival, although it is thought that pre-existing disease, or co-morbidity, is likely to be of prognostic importance (Milzman, et al., 1993; Phillips & Knaus, 1990). There is no data to suggest that pre-existing disease predicts long-term outcome or psychosocial sequelae.

Sociodemographic factors such as age, gender, and race are essential to consider when attempting to explore patient outcomes (Phillips & Knaus, 1990). It is commonly acknowledged in the literature that age plays an important role in determining mortality for trauma patients but there is minimal data regarding the impact of age on psychosocial, LS, or QOL outcomes in the trauma population (Jaffin, et al., 1993).

Post-Trauma Outcomes

Outcome evaluation is essential in order to assess various aspects of critical care (Friedman, Boyce, & Bekes, 1992; Mata, et al., 1992). The majority of research efforts

directed toward the exploration of outcomes of trauma victims and critical care treatment have been focused on mortality as an outcome (Bergner, 1989; Mata, et al., 1992; Ridley & Wallace, 1990). However, this endpoint is recognized to demarcate only the most extreme changes in HS. Recommendations from the Second European Consensus Conference in Intensive Care Medicine, held in Paris in December of 1993, include the importance of looking beyond mortality in measuring the outcome of critically ill patients. Researchers are increasingly using instruments which are sensitive to subtle changes in a variety of domains (Epstein, Hall, Tognetti, Son, & Cognant, 1989). Measures of morbidity, functional status, work or leisure activities, relationships, psychological status, and quality of life have been identified as important outcomes of comprehensive injury care; however, these outcomes have not been widely studied in trauma survivors (Bergner, 1989; Suter, et al., 1994; Strohmyer, et al., 1993).

More recently, outcomes of medical care have come to be defined in terms of the degree to which a change in function or well-being meets that person's needs or expectations (Ware, 1992). It is interesting to note the recognition of the centrality of the patient's point of view in the measurement of medical outcomes, despite previously demonstrated discordance between personal experience of health and the objective measurement of disease, symptoms, or function (Ware, 1992).

Mortality

Research has demonstrated that 82-89% of severely injured trauma victims survive to hospital discharge (Frutiger, et al., 1991; Holbrook, et al., 1994; Morris, Sanchez, Bass, & MacKenzie, 1991). The Major Trauma Outcome Study which contained data for 80,544 trauma patients demonstrated an overall mortality rate of 9% (Champion, et al., 1990). Mortality has been shown to increase with increasing age in trauma victims (Robertson & Redmond, 1991).

Morbidity

Long-term outcomes research has demonstrated that head and spinal cord injuries result in the greatest degree of disability. Also, although significant extremity injuries are seldom fatal, they carry a substantial degree of morbidity in relation to disability (Rhodes, Aronson, Moerkirk, & Petrash, 1988).

One study indicated that important outcomes to consider are the effects of missed injuries (Laasonen & Kivioja, 1991). These authors, in conducting a study of 340 trauma patients admitted to an ICU in Helsinki, found that 4.2% or 45 injuries were initially missed. In another study, investigators found that 16% of the trauma survivors had missed injuries, although all were minor (Frutiger, et al., 1991).

Depression has been noted in some studies as one area of morbidity in the post-trauma population (Chelluri, Pinsky, Donahoe, & Grenvik, 1993; Holbrook, et al., 1994). Holbrook et al. (1994) found that 81% of major trauma victims were depressed at discharge, according to the CES-D (Center for Epidemiologic Studies - Depression) score, and 43% were depressed at the 3 month follow-up. Chelluri et al. (1993) found that the CES-D score was high at one month after hospital discharge but decreased to the level reported in the general community by the end of one year.

Functional Status

Several investigators have found that although functional status for trauma survivors is usually decreased at one to three month follow-ups compared to pre-admission scores, by six months to a year, most patients return to pre-admission level (Holbrook, et al., 1994; Ridley & Wallace, 1990; Strohmyer, et al., 1993; Zaren & Hedstrand, 1987). Similarly, studies conducted to determine the degree of disability post intensive care admission in the elderly have demonstrated that among the survivors at one year post discharge, there is minimal change from reported pre-injury functional status (Kass, et al., 1992).

Work

The data from a five year follow-up study demonstrated that 79% of 167 trauma patients admitted to an ICU who received complete follow-up eventually returned to work, however, 11% had been forced to change their original occupation and 35% reported significant problems at work (Frutiger, et al., 1991). The authors comment that this study was conducted in Switzerland, where unemployment was almost nonexistent. Another study of severely injured trauma patients (those with hospital charges of over \$100,000) was conducted in order to determine factors which influence return to productivity (employment) (Morris, et al., 1991). These authors discovered that 59% of trauma survivors in their sample had some type of functional limitation in one or more of the following dimensions: self-care, mobility, and physical capabilities. These findings seem to contradict other studies reporting good functional recovery by one year post injury, however, most of those with functional impairment had sustained head or spinal cord injuries. Ninety-five percent of their population was productive pre-injury and 55% post-injury. Injury severity did not appear to predict functional recovery and return to work after multiple trauma (Holbrook, et al., 1994). Non-medical factors such as family support, motivation, and the ability to access support services must therefore be the primary contributors to productive outcome (Holbrook, et al., 1994; Morris, et al., 1991).

Psychosocial Outcomes

The overall physical and emotional consequences of trauma are devastating for those injured, their families and friends, as well as medical professionals (Baker, et al., 1992; Robertson & Redmond, 1991). The effect of a traumatic event on psychological dimensions is not a simple function of the event itself, but a complex function of individual control over what happens. A major predictor of positive versus negative effects of traumatic events involves whether an aversive event is escapable or not (Waites, 1993). The shock of initial trauma is, to a great extent, a function of its novelty and unexpectedness, whereby the victim has no chance to strengthen defenses (Waites, 1993).

Traumas caused by human actions (i.e., stabbings, motor vehicle collision from drunk driving) tend to elicit more severe responses than traumas of natural origin (i.e., caused by natural disasters) (Tanaka, 1988).

Dramatic permanent alterations in the lifestyle and ability to function of trauma survivors can occur. As a result, roles change, life goals are put on hold or change direction, and relationships develop a different focus (Klauber, 1993). Although physical adjustment to trauma occurs within the first year post-injury, psychological adaptation appears to continue beyond one year (Neff & Kidd, 1993; Strohmyer, et al., 1993). The emotional, cognitive, and psychosocial effects also create the most significant concerns for survivors of traumatic head injuries (Klauber, 1993).

Quality of Life

QOL is an individual's perception of their position in life, in relation to their goals, and the value system which they have accepted and incorporated into their decision-making (Read, 1993). QOL represents a broad range of dimensions of human experience ranging from those associated with the necessities of life to those associated with achieving a sense of fulfillment and personal happiness (Read, 1993). General components of QOL include personal safety, health, social participation, access to goods and services, housing, aspects of the physical environment, quality of working life, employment, individual development through learning, time and leisure use, and justice.

It is important to measure QOL because physiologic measures which are important to clinicians are of limited interest to patients, and are often poorly correlated with role function, LS, and emotional well-being (Guyatt, Feeny, & Patrick, 1993). The ethical imperative for exploring or measuring this construct rests on the assumption that QOL measures will result in QOL improvements (Faden & Leplege, 1992).

Reports of QOL after critical illness vary. The primary reasons for this high variability in results are that the conceptual and operational definitions of QOL are very different between studies. There is no apparent consensus in the literature, and a

phenomenal number of instruments purporting to measure QOL are used, making it difficult to compare between studies. Several studies have shown that trauma or intensive care survivors report very little change in QOL at one year follow-up visits (Ridley, Biggam, & Stone, 1994; Yinnon, Zimran, & Hershko, 1989). However, these studies use different measures to assess QOL (i.e., measures of functional status or level of independence) and a significant potential for recall bias exists in asking the individuals to report their pre-illness QOL up to a year post injury. Other studies have demonstrated significant reductions in QOL for trauma survivors, from one to five years post -injury (Ridley & Wallace, 1990; Thiagarajan, Taylor, Hogbin, & Ridley, 1994). These studies also contain significant potential for recall bias in reporting pre-injury QOL. They also tend to focus on the more subjective aspects of QOL and have samples with a high number of severe head injuries.

Life Satisfaction

Definition of Life Satisfaction

Health care professionals are often interested in how their patients lives have progressed, whether their future prospects are positive, and whether they are happy and have a good sense of well-being (Royse, Rompf, & Dhooper, 1991). LS has been described as a component of subjective well-being (Royse, et al., 1991). It has also been equated with the terms QOL and well-being (Rathbone, Horsely, & Goacher, 1994). LS is more often described as one of a set of constructs defining QOL and is receiving increasing interest from clinicians and researchers in the field of health sciences (Kreitler, Chaitchik, Rapoport, Kreitler, & Algor, 1993). More specifically, LS and well-being comprise the perceptual components of QOL, versus the functional and symptomatic components. It appears to involve the integration of past life experiences with current circumstance in relation to both cultural and environmental influences (Baiyewu & Jegede, 1992).

Factors Associated With Life Satisfaction

Exploring the correlates and predictors of subjective well-being has for decades been a major investigational focus in relation to social issues in the elderly (Markides & Lee, 1990; McCulloch, 1991). Psychological stress and well-being have been closely correlated with LS. They are reported to be negative and positive affective states, which focus on the quality of the feelings themselves and not on making diagnostic classifications (Ware, 1992). Investigators exploring the predictors of self-rated health and LS in the general population found that psychological distress had the largest direct effect on LS, and that fear of unemployment had a direct negative effect (Fylkesnes & Forde, 1992). The nature of social relationships, stability and congruency of role expectations, and objective circumstances have been shown to correlate more highly with happiness and LS than general health (Najman, et al., 1981).

Other factors such as income, education, leisure satisfaction, self-esteem, bereavement, and marital status have also been associated with LS, but each domain shows significant variability in the degree of association between studies (Baiyewu & Jegede, 1992; Kinney & Coyle, 1992; Kreitler, et al., 1993). On a general level, it appears that although domains such as health and social relations have a higher potential contribution to reports of LS, LS is not dependent on any one or more specific factors, but rather is a function of the individual's situation, which in turn dictates the degree of contribution of any one domain to overall LS (Kreitler, et al., 1993).

The relationship of health and LS is very interesting (Kreitler, et al., 1993). Intuitively, it would seem that LS would be closely related to good health. However, individuals with major disabilities or loss of motor function due to traumatic paralysis do not differ in LS scores from healthy individuals in the general population (Fuhrer, Rintala, Hart, & Young, 1992; Kinney & Coyle, 1992; Kreitler, et al., 1993). The elderly have indicated a level of LS only slightly below the general population, and some studies involving victims of cancer have shown even this group of individuals to have higher LS

scores than the general population (Kreitler, et al., 1993). It has been suggested that a certain level of LS is necessary for the maintenance of daily psychological and physical functioning, or for preventing the onset of depression (Kreitler, et al., 1993). It appears then, that some degree of LS exists within most people due to the tendency to maintain hope and optimism, even in the face of illness and daily life challenges. What may differ between people is the domains that they refer to in reporting or generating LS scores. Those who are healthy would have to consider relatively few domains to be able to report positive LS, whereas individuals with illness or challenging circumstances would have to consider several domains in order to be able to report an acceptable degree of LS (Kreitler, et al., 1993).

Findings from a research study that was conducted in order to explore the differences in LS among cancer patients versus healthy individuals and orthopaedic patients indicated that LS did not differ between groups, however, the basis on which LS is maintained did differ (Kreitler, et al., 1993). Those who were ill based their assessments on a larger number of domains than orthopaedic patients or healthy individuals.

One group of investigators found that self ratings of LS were the highest for those individuals without a history of traumatic experiences (including both physical and psychological trauma) (Royse, et al., 1991).

Self-Rated Health

It is well recognized in the literature that self-rated health is a complex construct (Smith, Shelley, & Dennerstein, 1994). There is considerable interest in the current literature with regard to the validity of self-reports in the measurement of HS, as well as the exploration of the determinants and correlates of self-evaluated health (Fylkesnes & Forde, 1992; Smith, et al., 1994; Wannamethee & Shaper, 1991). Health perceptions are personal beliefs and evaluations of HS which focus on health in general rather than on

specific components. They integrate information about health taking into account differences in health preferences, values, needs, and attitudes (Ware, 1992).

Self-rated health is purported to represent a summary of how various aspects of health are perceived by the individuals (Fylkesnes & Forde, 1992). Research has consistently demonstrated that self-reported health is strongly correlated with mortality and survival (Fylkesnes & Forde, 1992; Wannamethee & Shaper, 1991). It has also demonstrated stability over time and has consistently predicted health services utilization (Johnson & Wolinsky, 1993)(Smith, et al., 1994). The discordance between clinician and patient assessments of physical and mental HS also provides impetus for utilization of self-report measures (Kwoh, O'Connor, Regan-Smith, Olmstead, Brown, Burnett, et al., 1992).

Determinants of Self-Evaluated Health Status

One of the most widely used measures of HS consists of a single item which requires respondents to rate their health as excellent, good, fair, poor, or very poor (Fylkesnes & Forde, 1992; Krause & Jay, 1994). This measure has been widely employed primarily due to ease of administration and ability to reflect the diverse components of health in a single measure (Krause & Jay, 1994).

Krause and Jay (1994), through in-depth interviews, used open-ended probes with a sample of 192 members of the general population aged 14-92 years in order to explore the referents used in rating HS with global measures. These authors found that those in the youngest age group (14-24) were more likely to use health behaviors as a referent than those over 60. In contrast, those over 25 were more likely to be thinking about health problems when they responded. The authors conclude that the global health item may be interpreted in a variety of ways and that the tendency to use a particular referent may not be distributed randomly in the population (Krause & Jay, 1994).

Other investigators have found that reports of worse health are almost entirely related to the physical experience of adverse health (symptoms, medication use, and past surgery) whereas better health is related to presence or absence of illness to a limited degree (Smith, et al., 1994). Thus, those who are ill appear to use medically related concerns to define their level of health, whereas other individuals define health in terms of considerations which extend beyond the scope of traditionally defined dimensions.

The Tromso Study was conducted on the premise that the manner in which an individual evaluates health is shaped by sociocultural and psychosocial factors (Fylkesnes & Forde, 1991). In this study, results from surveying the majority of the population of men aged 20-61 and women aged 20-56 within the municipality of Tromso, Norway indicated that the best predictor of self-evaluated health in men and women was the individual's perception of somatic symptoms and disease connected to the musculoskeletal system. The authors state that this finding, considered together with the direct and strong positive effect of leisure time activities and workload, suggests that physical performance and general well-being are the primary dimensions of perceived health (Fylkesnes & Forde, 1991).

In summary, using self-reports to measure HS is receiving considerable interest in the current literature. Among the measures utilized in determination of self-reported health, a single item, global measure currently appears to be well accepted due to ease of administration and ability to reflect the influence of a variety of domains. The particular referents that individuals use, or domains that they consider, in reporting their health has been shown to vary between individuals and between groups. Those who are ill rate their health more heavily in terms of the medically defined domains than healthy individuals.

Summary - Gaps in Knowledge

From the above review of the literature, it is apparent that trauma is a serious and common problem facing society. With the exception of mortality, there is insufficient knowledge regarding the long-term outcomes of trauma in survivors. It appears that

physical health is satisfactory at one year post injury for the vast majority of trauma survivors. Exceptions seem to be the head and spinal cord injured groups who continue to demonstrate a high incidence of functional disability at one year post injury. However, several studies have indicated that despite adequate functional ability, trauma survivors may have ongoing concerns in the areas of psychosocial function and adaptation at one year post injury. These studies have been methodologically flawed, however, making these conclusions tenuous. It is well recognized that QOL is an important area to be addressed in future research efforts. Some investigators have attempted to measure QOL as an outcome in post-trauma or post-intensive care patients, however, these studies have been plagued with methodological weakness. The methodological issues are often attributable to lack of adequate conceptual and operational definitions of this construct and the inability to obtain an accurate baseline QOL score. LS, as a perceptual component of QOL, and self-reported health, have not been adequately addressed as long-term outcomes in the adult trauma population in relation to differences between people, as well as differences in domains utilized in reporting LS and HS. Psychosocial well-being is an important area to study in the population of trauma survivors.

CHAPTER 2

METHODS

The contents of this chapter include an outline of the specific study aims, the methods employed in identifying and recruiting the study sample, description of the development and pre-testing of the questionnaire, the methods used in analyzing the data, and the ethical considerations specific to this study.

Specific Aims

From the preceding review of the literature, the following specific aims for study were identified:

- 1) To describe the self-reported HS of trauma survivors at least one year post injury.
- 2) To describe the LS of trauma survivors at least one year post injury.
- 3) To explore the relationships between Illness Intrusiveness, self-reported health, and LS among trauma survivors.
- 4) To describe the domains or referents that trauma survivors use in reporting their HS and LS.
- 5) To describe the similarities and differences between the domains rated as important to health and LS from the responses to open-ended questions and to item responses to the Illness Intrusiveness Scale and the Sickness Impact Profile (SIP).

Method

A cross-sectional, survey design was employed for this study. The sampling frame consisted of all adult (at least 18 years of age at the time of study) trauma patients entered into the Alberta Trauma Registry of the Calgary General and Foothills Hospitals between April 1, 1993 and March 31, 1994. This yielded a sampling frame containing 562 patients. A trauma patient, for the purposes of the study, was defined as one entered into the Alberta Trauma Registry, which contains data on all patients who have an ISS of greater than or equal to 12. Thus, this data base is limited to those with moderate to severe trauma, and therefore, contains only a small proportion of all trauma patients. Data for

the Registry are collected prospectively from chart review at the time of admission, and entered by the Trauma Coordinators at each site. Those who are responsible for coding and entering the data into the computer have taken a formal course in the United States to train them in this coding system. The Trauma Coordinators have a built in system for reliability checks whereby charts are reviewed again prior to patient discharge in order to identify any information missed at the time of admission. Any such additional information is added to the data base and severity of injury indices are revised accordingly.

From the Registry, data were collected on all individuals registered within the specified time frame, including age, sex, injury class (blunt, penetrating, or burn), mechanism of injury (e.g., motor vehicle injury), hospital and intensive care length of stay (LOS), GCS at admission, ISS, RTS, and disposition (i.e., patient destination after hospital discharge, e.g., home, rehabilitation facility). The type and extent of injuries were entered into the computer by the Trauma Coordinators at each site from documentation on patients' charts. The resulting ISS and RTS were computer generated. Names, hospital identification numbers, telephone numbers, and addresses were collected on all individuals meeting the following inclusion and exclusion criteria:

Inclusion Criteria:

- 1) At least 18 years of age at time of interview,
- 2) Patients with an ISS of at least 12,
- 3) Trauma occurred at least one year prior to interview,
- 4) Alive at time of follow-up,
- 5) Informed consent,
- 6) Subjects were reached after 5 telephone contact attempts at the most recently available number;

Exclusion Criteria:

- 1) Probable cognitive impairment (initial GCS of 8 or less),
- 2) Spinal cord injury,

- 3) Current residence outside of Calgary,
- 4) No telephone number.

A list of the trauma survivors who met entrance criteria was generated by the Trauma Coordinators of the Calgary General and Foothills Hospitals. An additional list of ineligible individuals who were injured and entered into the Trauma Registry during the study time frame was generated and provided without identifiers, in the form of anonymous aggregate data, in order to provide information on the reason for exclusion from the present study. All eligible individuals were first sent a letter from the Director of the Trauma Services of the Calgary General and Foothills Hospitals in order to briefly introduce the study, outline the individual's role should they choose to participate, and provide an opportunity for individuals to telephone and refuse prior to being contacted by the study personnel (Appendix A). One week after the letters were mailed, attempts to contact subjects by telephone were initiated.

Telephone numbers were initially identified through the Trauma Registry records. When telephone numbers were not available through the Registry, or, when the numbers obtained proved incorrect upon initial attempts at telephone contact, a search by hospital identification number was conducted in the Medical Records department of each study institution for updated telephone numbers and addresses. When the search via Medical Records was unsuccessful, or when the updated numbers were not currently correct, local telephone books and directory assistance were consulted with the most recent address available in attempt to match addresses with telephone numbers. Individuals were excluded from the study if no accurate telephone number was available following the institution of the above measures.

Telephone calls were made on varying days of the week (Monday to Sunday) and at varying times of the day (morning, afternoon, and evening), such that all calls to one individual were placed on a different day of the week, and no more than 2 attempts were

made at the same time in the day. A two week period was used to provide 5 telephone contact attempts to each individual, if required.

Once individuals were reached by telephone, the study was explained in further detail, any questions were addressed, and verbal consent to interview was sought (Appendix B). Those who refused were asked for a reason for refusal and asked to respond to two questions on global health and LS in order to compare respondents and non-respondents with respect to outcome. Those who expressed interest in participating were scheduled for an interview at either the Calgary General or Foothills Hospitals. Only the elderly and women who expressed difficulty in traveling to the interview (e.g., due to inability to drive or care giving responsibilities) were offered the additional option of a home interview. Home interviews were not offered to men under the age of 60 due to interviewer safety considerations. One female interviewer was conducting all interviews. Formal, written consent was obtained at the time of the interview (Appendix C).

Measurement

Several standard measures were combined in order to assess self-reported HS and LS in trauma survivors.

Life Satisfaction

- 1) Global LS rating: The following single item measure of LS was used: 'How much satisfaction and enjoyment of life do you generally feel? A lot of satisfaction and enjoyment/Fairly much satisfaction and enjoyment/Very little satisfaction and enjoyment/Absolutely no satisfaction and enjoyment.' The alternatives were scored 1-4 respectively. Test-retest reliability over 3 months in a sample of 50 healthy individuals was $r = 0.92$ (Kreitler, et al., 1993). This single item measure was included to provide a global evaluation of LS.
- 2) The response to the single item question on LS was followed by open-ended probes in order to elicit an explanation for the individual's response to the closed-ended query.

Self-Reported Health Status

- 1) Global health rating: Participants were asked to rate their health as excellent, very good, good, fair, or poor. This measure has previously been shown to independently predict mortality and survival, and to be stable over time (Fylkesnes & Forde, 1991; Fylkesnes & Forde, 1992). It is purported to represent a summary of how various aspects of health are perceived by the individual, providing a more global picture than traditional disease-oriented conceptions would suggest (Fylkesnes & Forde, 1992).
- 2) The response to the single item question was followed by open-ended probes in order to elicit an explanation for the individual's response to the closed-ended query. With the use of open-ended probes, the conceptual foundations for global ratings were not restricted by *a priori* assumptions about factors which influence health perceptions. As well, these probes provided better insight into the meanings attached to subjective health ratings because the participants provided responses in their own words (Krause & Jay, 1994).
- 3) Sickness Impact Profile: The SIP is comprised of 136 items directed at assessing an individual's perception of his performance of activities in 12 categories (Appendix D). Ambulation, mobility, and body care and movement are the three categories which are used to assess one's physical dimension of health. Communication, alertness behavior, emotional behavior, and social interaction are the four categories used to assess the dimension of psychosocial functioning. The remaining independent categories include sleep and rest, eating, work, home management, and recreation and pastimes. Subjects are to respond to only the items which they feel describe them at the time the profile is done and are related to their health.

The SIP was chosen for inclusion in the study instrument for a number of reasons. It is recommended that currently existing generic health and disease-specific measures be evaluated for application in assessing outcomes in the critically ill population, and the SIP is one of the best known and validated instruments for general health measurement (Ridley

& Wallace, 1990; Suter, et al., 1994). The SIP provides a broad measure of perceived HS, is thought to be sensitive to differences in HS that occur over time and between groups, and is broadly applicable across type and severity of illness, and across demographic and cultural subgroups (De Bruin, Diederiks, De Witte, Stevens, & Philipsen, 1994; Oye, Landefeld, & Jayes, 1990). It has also been recommended for evaluation in the measurement of outcome in survivors of intensive care (Friedman, et al., 1992). Test-retest reliability for the SIP (136-item version) in various trials has been consistently high (0.88-0.92) for the overall score. Reliability has been higher for the interviewer-administered (0.97) than the self-administered version (0.87). Internal consistency (Cronbach's coefficient alpha) was 0.94 for the 136-item version. This measure provided opportunity to explore the contribution of various domains to HS and enabled the determination of degree of correlation between a single-item, global report of health and LS and this validated tool.

Illness Intrusiveness and Perceived Control

1) **Illness Intrusiveness Scale:** This scale, which was incorporated into the study instrument, provided an assessment of the degree to which consequences of traumatic injury impede interests and activities in a variety of domains important to perceived QOL, and allowed for comparison to ratings of HS and LS (Appendix D). The scale is divided into two distinct sections which are scored separately. In the first section, subjects are asked to rate each of 13 life domains (work, active recreation, passive recreation, financial situation, relationship with spouse, sex life, family relations, other social relations, self-expression/self-improvement, religious expression, community and civic involvement, health and diet) on a scale from 1 to 7 reflecting the degree to which the effects of the trauma disrupt interests and activities that they value (1 meaning not very much, 7 meaning very much). These ratings are summed to provide a total Illness Intrusiveness score. Test-retest reliability on the total Illness Intrusiveness score (first section of the scale) was 0.79 in a population of end-stage renal patients (coefficient alphas 0.81-0.85)

(Devins, Binik, Hutchinson, Hollomby, Barre, & Guttman, 1983-84; Devins, Mandin, Hons, Burgess, Klassen, Taub, et al., 1990). In the second section, subjects are asked to rate the same 13 life domains on the degree to which they feel they have control over these areas of life (1 meaning no control, 7 meaning a great deal of control). Ratings for the 13 domains are summed to provide a total perceived control score.

Pre-Testing of Instrument

The study instrument (Appendix D) was compiled into a structured questionnaire, including questions on global HS and LS, open-ended clarification, the Illness Intrusiveness Scale, and the SIP. The questionnaire was pre-tested in five healthy individuals. The individuals were selected by convenience and ranged in age from 20 to 78 years. The purpose of pre-testing the instrument was to detect potential problems prior to administration to study participants and to estimate the time required for the interview. The interview, including the time required to obtain consent, took approximately 40 to 60 minutes to complete. There were no identified problems with questionnaire administration. Although these were healthy individuals, the exclusion criteria for the study suggested that the participants would also likely be relatively healthy.

Data Collection

Personal interview was the method of choice for instrument administration for a number of reasons. One of the most important reasons was that not all of the instruments chosen for administration (i.e., the Illness Intrusiveness Scale) have been validated for self-administration or for telephone administration. The SIP has a higher reliability when used in a personal interview format than when self-administered (De Bruin, et al., 1994). As well, the time requirement identified through pre-testing of the instrument made personal interviews appear more feasible than telephone or self-administration with respect to respondent burden. Personal interviews were also chosen in order to minimize the potential for missing items and for misunderstandings. The personal interview format also

allowed for response to non-verbal cues through the use of probes as necessary to clarify and expand subject responses.

Analysis

As the data was collected, it was entered into the Epi Info Version 6 data entry system (Dean, Dean, Coulombier, Brendel, Smith, Burton, et al., 1994). All individuals were assigned a study identification number. Information from the study questionnaire and the variables collected from the Trauma Registry were entered by study identification number.

Data were analyzed using the Epi Info Version 6 statistics system (Dean, et al., 1994). Data from the Trauma Registry (demographic variables, injury type and severity, disposition post hospital discharge, and hospital and ICU LOS) were categorized and cross tabulations were used to explore for any differences between respondents and non-respondents. Cross tabulations were also used to compare respondents and non-respondents with respect to the outcomes of global health and LS ratings for the non-respondents who chose to answer these questions by telephone upon refusal to enter study. Data from the Registry and from the study questionnaire for respondents were then collapsed and analyzed by frequency distributions and cross tabulations to determine the characteristics of the study population. Decisions with respect to cut points for constructing two by two tables for analysis were made by inspecting the distributions for clinically meaningful cutpoints and to ensure sufficient numbers in each group.

The responses to the global health and LS questions were analyzed by frequencies and then cross tabulated with the variables identified through the Registry to explore for potential associations. The Illness Intrusiveness Scale and the SIP were analyzed via frequencies to describe individual domains, then summed across domains to provide composite measures. Within the SIP, each category, or domain, is comprised of the scores of varying numbers of questions, weighted to relative importance. A score representing the physical dimension of health is composed of the sum of individual

category scores which are related to physical aspects of life, including body care and movement, mobility, and ambulation. The physical score is calculated by summing scores across the 3 categories specified above, dividing this score by the total possible score for these categories (356.4), then multiplying that number by 100. The psychosocial score is again a composite score, reflecting the impact of sickness on psychosocial areas of function. This score is obtained by summing the scores from the categories of communication, alertness behavior, emotional behavior, and social interaction. This number is then divided by the total possible score for all 4 categories (365.7) and then multiplied by 100. The total SIP score is a score intended to reflect the impact of sickness on the 12 categories reflecting functioning in relation to a variety of life dimensions and is obtained by summing across all 12 categories, dividing that number by the total possible score for all categories (1003), then multiplying by 100. Cross tabulations and correlation coefficients were used to explore for potential associations between the key variables of self reported HS, LS, Illness Intrusiveness, perceived control, and the impact of sickness on various life domains. Cross-tabulations were used to explore for associations between the key variables mentioned above, the demographic variables obtained through the Registry, and remaining study variables (marital status, number of children, whether or not participants were primary caregivers of their children, pre-injury and current employment status, whether or not a change in work status was attributed to the injury, education level, pre-injury illness, and involvement in litigation). These additional variables were explored for potential associations because they were identified through the literature review to be potential confounders of long-term outcomes of trauma survivors. For the purposes of analysis, the Illness Intrusiveness and perceived control total scores were assumed to be continuous data.

Although this is a descriptive study, Chi square and Fisher Exact tests of statistical significance were calculated and presented for the sole purpose of exploring the strength

of potential associations. Statistical significance was not determined as a means to test hypotheses.

The responses to the open-ended clarification of the global health and LS questions were analyzed by an open coding process (Strauss & Corbin, 1990). This coding process was used to break down the data and form categories around the phenomena of perceptions of health and satisfaction with life. The data were then put back together by linking categories and subcategories. The core categories were then identified and presented descriptively in an attempt to clarify and add depth to the closed ended queries presented first in the study questionnaire.

Ethical Considerations

Respect for Persons

A three-step consent process was employed. All potential participants were sent a letter from the Trauma Directors of each study institution which described the study and provided a telephone number for refusal if they did not want to be contacted by telephone (Appendix A). Trauma survivors, who met study entrance criteria and had not called to refuse participation in response to the letter, were contacted by the investigator and asked for verbal consent to participate (Appendix B). Written consent was obtained at the time of the interview for all participants (Appendix C). Subjects thus had 3 opportunities to refuse to participate.

Participation in this study was informed and voluntary, and all participants were told that they could terminate the interview at any time. Anonymity and confidentiality were maintained through documentation by study identification numbers and through reporting of pooled results only.

Beneficence/Maleficence

There was no intentional harm done to any study participants. Potential benefits to study participants arise through attainment of knowledge and understanding which will

form the basis for future research efforts toward improving the health and LS of trauma survivors.

Justice

The population of trauma survivors have been minimally researched. This group of individuals deserved the opportunity to participate and reap the benefits of research efforts.

Ethical Approval

Prior to initiation of this study, the research proposal was submitted to, and received approval from, the Centre for Advancement of Health and the Research and Development Committee of the Foothills Hospital, the Research and Development Committee of the Calgary General Hospital, and the Conjoint Medical Ethics Committee of the University of Calgary.

CHAPTER 3

RESULTS

There were 562 individuals, with an ISS of at least 12, who were identified through the Trauma Registry of the Calgary General and Foothills Hospitals for the period from April 1, 1993 to March 31, 1994. This time period was chosen so individuals would be approximately one to two years post injury at the time of the study. The study period began May 1, 1995 and ended June 15, 1995. Of the 562 individuals, 473 were ineligible for one or more reasons (Table 1).

Table 1 Reasons for Exclusion
(473 persons; more than one reason per person possible)

Reason for Exclusion	Total N Excluded
Under 18 years of age at study onset	13
Deceased at study onset	89
GCS score of 8 or less on admission	145
Spinal cord injury	16
Current residence outside of Calgary	252
No available telephone number	106

Only 2 of the 89 individuals deceased at study onset had died after hospital discharge. Following the exclusion of ineligible individuals as outlined above, 89 individuals were identified as eligible for participation in the study. Twelve people could not be reached after 5 attempts to contact by telephone. Of the 77 individuals who were contacted, 49 agreed to participate and were subsequently interviewed, providing a response rate of 63.6%. The reasons for refusal to participate in the study are displayed in Table 2.

Table 2 Reasons for Refusal to Participate

Reason for Refusal	Number
Too busy/No time	10
No reason provided/Not interested	4
Does not speak any English	3
Family member refused on behalf of patient	3
Involved in litigation/Lawyers advised against participation	2
Too ill (physically or mentally)	2
Denied injury	1
Away traveling	1
Satisfied with care	1
No funds for transportation to interview	1
Total	28

Comparison of Respondents to Non-Respondents

The following section contains information comparing the 49 study participants to the 28 individuals who were contacted and refused participation in this study.

Respondents and non-respondents were compared with respect to age, sex, number of telephone contacts required to reach potential participants, time since injury, class and mechanism of injury, LOS in hospital and the ICU, GCS, ISS, RTS, disposition upon hospital discharge, and self reports of LS and overall HS.

Age

The respondents ranged in age from 18 to 88 years of age with a median of 33 years. This was not significantly different from the age of the non-respondents which ranged from 18 to 92 years of age with a median of 43.5 years ($p = 0.11$). The majority of trauma survivors were between 25 and 44 years of age for both respondents and non-respondents.

Table 3 Age Distribution Among Respondents and Non-Respondents

	Respondent	Non-Respondent	Total
18-24	9	2	11
25-44	25	12	37
45-64	7	10	17
65+	8	4	12
Total	49	28	77

Sex

Among respondents and non-respondents eligible for participation, there were more males (67.5%) than females (32.5%). Respondents were 63.3% male and non-respondents were 75% male. This difference is not statistically significant ($p = 0.42$).

Table 4 Sex by Respondent

	Respondent N(%)	Non-Respondent N(%)	Total N(%)
Male	31(63.3%)	21(75%)	52(67.5%)
Female	18(36.7%)	7(25%)	25(32.5%)
Total	49(100%)	28(100%)	77(100%)

Mechanism of Injury

Table 5 illustrates that the majority of both respondents and non-respondents sustained either a moving vehicle injury (motor vehicle, pedestrian, or bicycle accident) (21/49 or 42.9% of respondents and 13/28 or 46.4% of non-respondents) or a fall (20/49 or 40.8% of respondents and 12/28 or 42.9% of non-respondents). Mechanism of injury was very similar between the 2 groups.

Table 5 Mechanism of Injury by Respondent

	Respondent	Non-Respondent	Total
Moving Vehicle	21	13	34
Fall	20	12	32
Violence	6	2	8
Other	2	1	3
Total	49	28	77

Other Demographic Characteristics

Table 6 below provides a summary of comparisons of several characteristics of the 49 respondents and 28 non-respondents. Respondents and non-respondents do not differ with respect to the number of telephone contacts required to reach these individuals, the amount of time that had elapsed between injury and study interview or refusal, injury class, hospital and ICU LOS, GCS, ISS, RTS, and disposition.

Table 6 Summary of Characteristics of Respondents (N=49) and Non-Respondents(N=28)

Variable	Respondents	Non-Respondents	Test of Association	p value*
Number of Telephone Contacts	Median 2	Median 1	Yates Corrected Chi square	0.85
Time Since Injury	Median 595 days	Median 597 days	Kruskal-Wallis	0.11
Injury Class N(%)	Blunt 45(91.8)	Blunt 26(92.9)	Fisher Exact 2-tailed	1.00
Hospital LOS	Median 10 days	Median 8.5 days	Kruskal-Wallis	0.64
ICU LOS N(%)	LOS=0 days 37(75.5)	LOS=0 days 25(89.3)	Yates Corrected Chi square	0.24
GCS** N(%)	Score=15 28(62.2)	Score=15 19(67.9)	Yates Corrected Chi square	0.44
ISS N(%)	Score>15 32(65.3)	Score>15 28(53.6)	Yates Corrected Chi square	0.44
RTS** N(%)	Score=7.8408 33(73.3)	Score=7.8408 23(82.1)	Yates Corrected Chi square	0.26
Disposition N(%)	Home 39(79.6)	Home 25(89.3)	Fisher Exact 2-tailed	0.35

* Level of significance 0.05

** Data available for only 45 respondents

Life Satisfaction and Self-Reported Health Status

Only 10 out of the 28 non-respondents (35.7%) agreed to answer the questions on LS and HS over the telephone, thus the responses of these 10 individuals may not be representative of the entire group of non-respondents.

The respondents reported their satisfaction with life as a lot of satisfaction and enjoyment more frequently (24/49 or 49%) than the 10 non-respondents (1/10 or 10%) (Table 7). Respondents and non-respondents differed with respect to ratings of LS, with non-respondents providing lower ratings ($p = 0.03$).

Table 7 Life Satisfaction Ratings by Respondent

	Respondent	Non-Respondent	Total
A Lot of Satisfaction and Enjoyment	24	1	25
Fairly Much/Little/Absolutely No Satisfaction and Enjoyment	25	9	34
Total	49	10	59

Table 8 illustrates that the distribution of ratings of HS among respondents and non-respondents did not differ ($p = 0.73$).

Table 8 Self-Reported Health Status Ratings by Respondent

	Respondent	Non-Respondent	Total
Excellent or Very Good	25	6	31
Good, Fair, or Poor	24	4	28
Total	49	10	59

In summary respondents and non-respondents did not differ with respect to age, sex, mechanism of injury, the number of telephone contacts required to reach these individuals, the amount of time that had elapsed between injury and interview or refusal, injury class, hospital and ICU LOS, GCS, ISS, RTS, and disposition after hospital discharge. Only 10 out of the 28 non-respondents chose to answer the questions on LS and HS over the telephone. Respondents did differ from the 10 non-respondents with respect to LS, with the non-respondents providing lower ratings of LS. The respondents did not differ from the 10 non-respondents with respect to their HS ratings.

Demographic Description of Study Participants

The following section provides a description of the demographic characteristics of the study participants, including age, sex, interview location, injury class, mechanism of injury, the number of telephone contacts required to reach these individuals, length of interviews, time since injury, hospital and ICU LOS, GCS, ISS, RTS, disposition, involvement in litigation, marital status, number of children the respondents have, whether or not they are primary caregivers of their children, pre-injury and current employment status, change of work status since injury, education level, and pre-injury illness.

Age and Sex

The age and sex of study participants was described previously in the section on comparison of respondents and non-respondents (Tables 3 and 4). There was not a statistically significant difference in the ages of male and female subjects ($p = 0.62$), however, there was a slightly larger percentage of males younger than 45 years (74.2%) than females (61.1%) (Table 9). Approximately half of the respondents fell into the 25-44 year old age group, and 18 out of these 25 individuals (72%) were male.

Table 9 Age by Sex

	Female N(%)	Male N(%)	Total N(%)
18-24	4(22.2%)	5(16.1%)	9(18.4%)
25-44	7(38.9%)	18(58.1%)	25(51.0%)
45-64	3(16.7%)	4(12.9%)	7(14.3%)
65+	4(22.2%)	4(12.9%)	8(16.3%)
Total	18(100%)	31(100%)	49(100%)

Interview Location

All participants were required to take part in a personal interview. The choice of interview location was fairly equally distributed among the 3 options, with the site of the Foothills Hospital being utilized slightly more frequently (19/49 or 38.8%) than the General Hospital or home location (15/49 or 30.6% each) (Table 10).

Table 10 Interview Location by Sex

	Female	Male	Total
Calgary General Hospital	3	12	15
Foothills Hospital	4	15	19
Home Interview	11	4	15
Total	18	31	49

Class and Mechanism of Injury

The vast majority of injuries sustained by study participants were blunt (45/49 or 91.8%) as opposed to penetrating (3/49 or 6.1%) or burn-related injuries (1/49 or 2%). Table 11 illustrates that approximately 80% of all injuries were due to motor vehicle accidents (38.8%) or falls (40.8%).

Table 11 Mechanism of Injury

Mechanism of Injury	Frequency	Percent
Motor Vehicle Accident	19	38.8%
Pedestrian	1	2.0%
Bicycle	1	2.0%
Fall	20	40.8%
Gunshot	1	2.0%
Stabbing	2	4.1%
Assault	3	6.1%
Machinery	1	2.0%
Burn	1	2.0%
Total	49	100.0%

Categories of the mechanism of injury were collapsed for descriptive and comparative purposes (Table 12). Fifty percent of female injuries were falls (9/18), with the next highest category being moving vehicle injury (motor vehicle, bicycle, or pedestrian accident) (7/18 or 38.9%). Fourteen out of 31 male injuries (45.2%) were due to moving vehicle accidents with the next most frequent mechanism of injury being falls (11/31 or 35.5%). The most frequent cause of injury differs between males and females. The mechanism of injury sustained by study participants did not differ by their respective ages ($p = 0.56$).

Table 12 Sex by Mechanism of Injury

	Female	Male	Total
Moving Vehicle	7	14	21
Fall	9	11	20
Violence	2	4	6
Other	0	2	2
Total	18	31	49

Family Situation

Fifty-one percent of the study participants were married or in common-law relationships (25/49), 34.7% (17/49) of respondents were never married, 4 individuals (8.2%) were widowed, and only 3 out of 49 individuals (6.1%) were divorced or separated. Approximately half of the study sample did not have children (46.9%), 36.7% had one or two children, and 16.3% reported having 3 or more children. Fourteen of the 26 participants (53.8%) who reported having children, also described themselves as being primary caregivers at the time of the interview.

Employment

Almost 70% (34/49) of the study participants were working (gainfully employed) prior to sustaining their injury (Table 13) as compared to only 51% (25/49) who were working at the time of the study interview (Table 14). Whether one was working prior to their injury was not associated with sex ($p = 0.20$), but was associated with the age of study participants ($p = 0.04$). Whether or not one was working at the time of the study interview was associated with both the sex ($p = 0.023$) and the age ($p = 0.006$) of the subjects. Only 80% of those working at the time of the study interview were working full-time hours, as compared to 97% who were working full-time hours prior to sustaining their injury.

Table 13 Pre-Injury Employment Status by Sex

	Employed Pre-Injury	Not Employed Pre-Injury	Total
Female	10	8	18
Male	24	7	31
Total	34	15	49

Table 14 Current Employment Status by Sex

	Employed Currently	Not Employed Currently	Total
Female	5	20	25
Male	13	11	24
Total	18	31	49

Twelve out of the 49 study participants (~25%) who were employed prior to sustaining their injury were no longer employed at the time of the injury (Table 15). There is a statistically significant association between being employed prior to the injury and being employed at the time of the study interview ($p = 0.01$).

Table 15 Pre-Injury by Current Employment Status

	Employed Currently	Not Employed Currently	Total
Employed Pre-Injury	22	12	34
Not Employed Pre-Injury	3	12	15
Total	25	24	49

At the time of the interview, 33 of the 49 study participants reported that they had either changed occupations, employment status, or the number of hours they were working after they were injured. Fourteen or 42% of these 33 individuals (6 females and 8 males) claimed that the change was attributable to the injury they sustained (Table 16). Males and females did not differ with respect to whether or not they attributed the change in work status to their injury ($p = 0.75$). There is also no evidence of a statistically significant association between age and change in work status in this sample ($p = 0.74$).

Table 16 Sex by Change in Work Status Attributable to Injury

	Change in Work Status Due to Injury	Change in Work Status Not Due to Injury	Total
Female	6	8	14
Male	8	11	19
Total	14	19	33

Education Level

Forty-one percent of study participants had not graduated from high school at the time of the interview. Almost 25% had a college diploma or university degree (Table 17). Education level was not associated with the age ($p = 0.93$) or the sex (Less than high school vs other; $p = 0.19$) of study participants.

Table 17 Education Level

Education Level	Frequency	Percent	Cumulative Percent
Grade 9 or Less	10	20.4%	20.4%
Some High School	10	20.4%	40.8%
High School Diploma	8	16.3%	57.1%
Some Post Secondary	9	18.4%	75.5%
College Diploma	7	14.3%	89.8%
University Degree	5	10.2%	100.0%
Total	49	100.0%	

Pre-Injury Illness

Forty-one percent of the study sample (20/49) reported having some type of illness prior to sustaining their injury. Table 18 lists the types of pre-injury illnesses reported by study participants.

Table 18 Type of Pre-Injury Illness

Type of Pre-Injury Illness	Frequency	Percent
Aneurysm, duodenal ulcer, valve replacement	1	5.0%
Aneurysm, heart surgery, back injury	1	5.0%
Anorexia, depression	1	5.0%
Asthma	4	20.0%
Bipolar disorder	1	5.0%
Diabetes	2	10.0%
Endometriosis, viral infection	1	5.0%
Glaucoma	1	5.0%
Hypertension, retropharyngeal abscess 2 years ago	1	5.0%
Lupus, Fibromyalgia	1	5.0%
Myocardial infarction 1992, Amyotrophic Lateral Sclerosis diagnosed June, 1993	1	5.0%
Pleurisy (distant)	1	5.0%
Pneumonia just prior to injury	1	5.0%
Removal of part of uterus, ovary, and cyst	1	5.0%
Spinal meningitis, lung cancer, alcohol abuse	1	5.0%
Thyroid surgery 4 times, renal failure, arthritis	1	5.0%
Total	20	100.0%

There is evidence of an association between age and the reports of pre-existing illness. The proportion of individuals with pre-existing illnesses tends to increase as age increases ($p = 0.02$) (Table 19). The presence of pre-existing illness was not related to the sex of the individuals in this study ($p = 0.49$).

Table 19 Age by Pre-Injury Illness

	Pre-Injury Illness	No Pre-Injury Illness	Total
18-24	3	6	9
25-44	8	17	25
45-64	3	4	7
65+	6	2	8
Total	20	29	49

In summary, the majority of study participants were males and were under the age of 45 years. Most subjects sustained blunt injuries as a result of moving vehicle injuries or falls. The interviews were equally distributed between the hospital and home sites. The interviews lasted a median time of 40 minutes and subjects were between 1.2 and 2.1 years

post injury. The median LOS in hospital was 10 days and most subjects did not require ICU care. The majority of these individuals had a GCS of 15, an ISS of 16 or greater, and a RTS of 7.8408. Most subjects were discharged home without home care from the hospital. Involvement in litigation at the time of the interview was reported by 22.4% of participants. Approximately half of the subjects were married or in common-law relationships and about half of the participants reported having children. Almost 70% were working pre-injury as compared to only 51% at the time of the interview. Fourteen out of 33 individuals who reported a change in work status post-injury attributed this change to their injury. Approximately 41% of study participants stated that they had not graduated from high school and 41% of subjects reported some type of pre-injury illness.

The following section consists of the presentation of the results of the global questions on LS and HS asked of the study participants. A description of the results and identification of potential associations between ratings of LS and HS with other variables measured in this study is presented.

Life Satisfaction

Almost 50% (24/49) of participants provided the most favorable rating in response to the question on LS (Table 20). Almost 90% (44/49) of respondents chose either a lot or fairly much satisfaction and enjoyment. Age was not associated with the ratings of satisfaction with life ($p = 0.80$) (Table 21), however, the distribution of ratings of LS between men and women were slightly different. Table 20 illustrates that the proportion of men giving a rating of a lot of satisfaction and enjoyment of life (18/31 or 58%) was higher than the proportion of women (6/18 or 33%). The data suggests a potential association between sex and ratings of LS, however, when collapsed into a 2X2 table for analysis (A lot of satisfaction and enjoyment vs other) there is no significant difference ($p = 0.17$).

Table 20 Life Satisfaction Ratings by Sex
(How much satisfaction and enjoyment of life do you generally feel?)

	Female	Male	Total
A lot of satisfaction and enjoyment	6	18	24
Fairly much satisfaction and enjoyment	9	11	20
Very little satisfaction and enjoyment	2	2	4
Absolutely no satisfaction and enjoyment	1	0	1
Total	18	31	49

Table 21 Age by Life Satisfaction Ratings

	A lot of satisfaction and enjoyment	Fairly much/Very little/Absolutely none	Total
18-24	5	4	9
25-44	11	14	25
45-64	3	4	7
65+	5	3	8
Total	24	25	49

LS is associated with mechanism of injury (Table 22). Study participants who suffered moving vehicle and violence related injuries reported lower ratings of LS than those who suffered falls. The numbers of individuals who were subject to other types of injuries is too small to comment on an association.

Table 22 Mechanism of Injury by Life Satisfaction

	A lot of satisfaction and enjoyment	Fairly much/Very little/Absolutely none	Total
Moving Vehicle	8	13	21
Fall	15	5	20
Violence	1	5	6
Other	0	2	2
Total	24	25	49

Table 23 illustrates the comparison of LS to variables identified through the literature to have potential associations with long-term outcomes of trauma survivors. For the purposes of analysis, the LS categories were collapsed into 2 categories; a lot of satisfaction and enjoyment and other. LS is not associated with injury class, the requirement of ICU care, hospital LOS, GCS, ISS, RTS, disposition after hospital

discharge, the amount of time between injury and interview, marital status, whether or not participants had children and whether they were primary caregivers of these children, pre-injury and current employment status, whether or not a change in work status was attributed to the injury, education level, pre-injury illness, and involvement in litigation.

Table 23 Summary of Comparisons of Life Satisfaction to Study Variables

Variable	Test of Association	p value*
Injury Class (Blunt vs other)	Fisher Exact 2-tailed	0.61
Requirement of ICU Care (0 days vs other)	Yates Corrected Chi square	0.36
Hospital LOS	Kruskal-Wallis	0.56
GCS (15 vs other)	Yates Corrected Chi square	0.30
ISS (>15 vs other)	Yates Corrected Chi square	0.48
RTS (7.8408 vs other)	Yates Corrected Chi square	0.15
Disposition (Home vs other)	Fisher Exact 2-tailed	0.73
Time Since Injury	Kruskal-Wallis	0.09
Marital Status (Married or Common-law vs other)	Yates Corrected Chi square	0.20
Number of Children (No children vs other)	Yates Corrected Chi square	0.66
Care giving Responsibility	Yates Corrected Chi square	0.98
Pre-Injury Employment Status	Yates Corrected Chi square	0.60
Current Employment Status	Yates Corrected Chi square	0.20
Change in Work Status	Yates Corrected Chi square	0.54
Education (Less than high school diploma vs other)	Yates Corrected Chi square	0.18
Pre-Injury Illness	Yates Corrected Chi square	0.68
Litigation	Yates Corrected Chi square	0.20

* Level of significance 0.05

In summary, LS is not associated with the age of study participants, but may be associated with sex (although not statistically significant). LS was compared with several study variables and there were no potential associations identified between LS and any of the above variables measured except mechanism of injury, with moving vehicle and violence related injuries being associated with lower ratings of LS.

Open-Ended Clarification of Life Satisfaction Ratings

Following the provision of a rating of satisfaction with life on a 4 point scale from a lot to absolutely no satisfaction and enjoyment of life, study participants were asked why they provided that particular rating of their LS. This question was posed in order to explore the referents that individuals use in describing their LS. The results of this question were categorized into the 6 main themes of attitudes, limitations, physical/emotional symptoms, personal life/social support, economic/job situation, and physical fitness, and will be presented accordingly (Table 24).

Attitudes

The category most frequently referred to by respondents in explaining the rationale behind their ratings of LS concerned the role of attitudes. The rationale for high ratings of LS was often that respondents are enjoying life, they appreciate life more since the accident, or that everything seems to be going well for them (n=17). Some individuals attributed their positive LS ratings to their optimistic outlook (n=5) or that the accident changed the way they look at life or reinforced their priorities (n=3). The category of attitudes was also referred to by individuals describing their reasons for being less satisfied with life, with some respondents explaining that they are not satisfied because of the fear of re-injuring themselves or fear for their safety (n=4) and others describing a disappointing feeling that they were not the same person since their injury (n=3).

Limitations

A large number of study participants cited their involvement in interests and activities, and the fact that they were not limited by their injuries in this area, as a primary

reason for favorable reports of LS (n=10). More commonly, being limited in activities and interests (i.e. sports, recreation, continuing education, crafts, etc.) was referred to as a reason for being less satisfied with life (n=11).

Physical/Emotional Symptoms

Several individuals attributed poorer LS ratings to their physical symptoms (n=14), including headaches or pain, disabilities, memory loss, side effects of medications, and difficulty with eating or speech. Emotional difficulties were also often blamed for decreased LS (n=5). Some participants stated that they were satisfied with life because the accident had not changed them (n=4).

Personal Life/Social Support

Marriage or family life (n=7) and spiritual or church life (n=2) were described as major contributing factors to being satisfied with life. LS ratings were also attributed to the presence or lack of support (n=5) and a poor social life (n=2).

Economic/Job Situation

Fulfillment or difficulty at work was responsible for many LS ratings (n=9). Lack of poverty or concerns of not enough money were the explanations provided for LS ratings by several others (n=4).

Physical Fitness

Only one individual attributed their high LS rating to being physically active.

Table 24 Referents Used in Reporting Life Satisfaction

Referent	n Positive	n Negative
Attitudes		
Enjoy life	17	
Positive outlook	5	
New perspective	3	
Do not hold back	2	
Comparison to others	1	
Fear		4
Not the same person		3
Not completely satisfied		1
Limitations		
Not limited in interests and activities	10	
Accept limitations	1	
Limited in interests and activities		11
Physical/Emotional Symptoms		
Physical symptoms decrease LS		14
Doctor visits/requiring medication		3
Emotional difficulty		5
Same as before injury	4	
Conscious of surroundings	1	
Personal Life/Social Support		
Marital/family life	7	
Spiritual/church life	2	
Support from friends	4	
Poor social life		2
Poor quality of life		1
Lack of support		1
Economic/Job Situation		
Fulfillment at work	6	
Not in poverty	3	
Not working/difficulty at work		3
Not enough money		1
Physical Fitness	1	

Self Reported Health Status

Table 25 illustrates the responses to the global HS question. Eighty-six percent of respondents (42/49) rated their HS as either excellent (8/49 or 16.3%), very good (17/49 or 34.7%), or good (17/49 or 34.7%), with the categories of very good and good being most frequently chosen. Study participants' ratings of their HS and LS are related, with high ratings of HS being associated with high ratings of LS and vice versa ($p = 0.003$) (Table 26).

Table 25 Health Status Ratings

	Frequency	Percent	Cumulative Percent
Excellent	8	16.3%	16.3%
Very good	17	34.7%	51.0%
Good	17	34.7%	85.7%
Fair	6	12.2%	98.0%
Poor	1	2.0%	100.0%
Total	49	100.0%	

Table 26 Health Status by Life Satisfaction

	A lot of satisfaction and enjoyment N(%)	Fairly much/Very little/ Absolutely none N(%)	Total N(%)
Excellent or Very Good	18(75%)	7(28%)	25(51%)
Good, Fair, or Poor	6(25%)	18(72%)	24(49%)
Total	24(100%)	25(100%)	49(100%)

Age is not associated with study participants' ratings of their overall HS ($p = 0.77$). The majority of men (17/31 or 54.8%) rated their HS as excellent or very good whereas the majority of female participants (10/18 or 55.6%) rated their HS as good, fair, or poor, suggesting a potential association between self-reported HS and sex (Table 27). This association is not statistically significant in this sample ($p = 0.69$).

Table 27 Health Status by Sex

	Female N(%)	Male N(%)	Total N(%)
Excellent or Very Good	8(44.4%)	17(54.8%)	25(51%)
Good, Fair, or Poor	10(55.6%)	14(45.2%)	24(49%)
Total	18(100%)	31(100%)	49(100%)

Table 28 illustrates that the majority of subjects who rated their health as excellent or very good had sustained falls and the majority of participants who rated their health as good, fair, or poor had suffered moving vehicle related injuries. As well, almost all of the individuals who suffered violence related injuries rated their health as good, fair, or poor. Mechanism of injury is related to self reports of HS among study participants whereby those who were involved in moving vehicle or violence related injuries provided lower reports of health than those who sustained falls.

Table 28 Health Status by Mechanism of Injury

	Excellent or Very Good	Good, Fair, or Poor	Total
Moving Vehicle	10	11	21
Fall	14	6	20
Violence	1	5	6
Other	0	2	2
Total	25	24	49

Table 29 presents the comparison of self reported HS among study participants to variables measured in the study, which were identified through a review of the literature to have possible associations with the long-term outcomes of trauma survivors. For the purpose of analysis, the HS ratings were collapsed into 2 categories; excellent or very good, and good, fair, or poor. The only variable that has a statistically significant association with HS is RTS, in which lower RTS (more severe injuries) are associated with lower ratings of HS. When HS is collapsed into the categories of excellent, very good, or good and fair or poor, the association between HS and RTS is not statistically significant.

Table 29 Summary of Comparison of Health Status to Study Variables

Variable	Test of Association	p value
Injury Class (Blunt vs other)	Fisher Exact 2-tailed	0.35
Requirement of ICU Care (0 days vs other)	Yates Corrected Chi square	0.80
Hospital LOS	Kruskal-Wallis	0.11
GCS (15 vs other)	Yates Corrected Chi square	0.20
ISS (>15 vs other)	Yates Corrected Chi square	0.92
RTS (7.8404 vs other)	Yates Corrected Chi square	0.03*
Disposition (Home vs other)	Fisher Exact 2-tailed	1.00
Time Since Injury	Kruskal-Wallis	0.40
Marital Status (Married or Common-law vs other)	Yates Corrected Chi square	0.88
Number of Children	Yates Corrected Chi square	0.89
Care giving Responsibility	Yates Corrected Chi square	0.24
Pre-Injury Employment Status	Yates Corrected Chi square	0.92
Current Employment Status	Yates Corrected Chi square	0.67
Change in Work Status	Yates Corrected Chi square	0.62
Education (Less than high school diploma vs other)	Yates Corrected Chi square	0.68
Pre-Injury Illness	Yates Corrected Chi square	0.12
Litigation	Yates Corrected Chi square	0.45

* Statistically significant at the 0.05 level of significance

In summary, study participants' ratings of overall HS are not associated with age, injury class, hospital LOS, requirement of ICU care, GCS, ISS, RTS, disposition, the amount of time elapsed between injury and study interview, marital status, whether or not subjects had children and whether they were primary caregivers of their children, pre-

injury and current employment status, whether one attributed a change in work status to their injury, education level, pre-injury illness, and involvement in litigation. Potential associations were identified between self reports of HS and sex (not statistically significant), HS and mechanism of injury, and HS and RTS.

Open-Ended Clarification of Self-Reported Health Status Ratings

The study participants were asked to explain their HS rating (from excellent to poor) in order to seek an understanding of the referents used by trauma survivors in evaluating their own health. The following section consists of the presentation of the compilation of responses provided by respondents. These responses were categorized into 6 main themes of physical/emotional symptoms, limitations, fitness, attitude, work concerns, and family/support, and will be presented accordingly (Table 30).

Physical/Emotional Symptoms

Many study participants indicated that the reason they reported high ratings of their health was due to the fact that they feel well physically or mentally, without sickness or physical problems (n=22). Physical symptoms was a category also referred to frequently by respondents who were providing reasons for lower health ratings. Low health ratings were frequently attributed to specific diseases or illnesses (i.e., diabetes, asthma, hypertension), disabilities from injuries, and getting worn down or sick easily (n=20). Poorer health ratings were also provided due to concerns with specific symptoms (n=22), with pain being the most common concern. Several individuals also attributed lower health ratings to being emotionally or mentally unwell (i.e., depression, stress) (n=5).

Limitations

Two individuals stated that they provided favorable HS ratings because they were not limited in their participation in hobbies and recreational activities that they enjoyed. Physical limitations in relation to activities, hobbies, and social life were more frequently cited as rationale for poorer health ratings (n=10).

Fitness

Several study participants related that being physically active or fit contributed to their good health (n=10). Being less active, feeling a lack of physical fitness, or being overweight was attributed to less than optimal health by several individuals (n=8).

Attitude

A positive attitude was considered a major contributor to good health among 4 study participants (i.e., will to overcome disabilities, positive outlook). One individual explained that comparing self to others made him realize what good health he had. Fear of over-taxing one's body was thought to reduce ratings of health for one individual.

Work Concerns

The fact that some individuals can not work, or find work much harder, was cited as a reason for less than optimal health ratings for 3 of the study participants.

Family/Support

One individual attributed a high rating of health to the enjoyment she received from caring for her children and another to the support of the medical professionals she encountered.

Table 30 Referents Used in Reporting Health Status

Referent	n Positive	n Negative
Physical/Emotional Symptoms		
Do not get sick	8	
Feel good	4	
Physically better	6	
No physical problems	3	
Mental wellness	1	
Specific diseases		5
Disabilities from injuries		5
Worn down easily		10
Specific symptoms		
Pain		12
Communication		1
Memory, concentration, comprehension, dizzy		5
Aging		2
Sex life		2
Requiring medication		1
Mentally unwell		5
Smoking		1
Limitations		
Not limited in hobbies/recreation	2	
Limited in hobbies/activities		10
Limited by confinement to wheelchair		1
Fitness		
Active/fit	10	
Take care of self/eat well	1	
Unfit		6
Overweight		2
Attitude		
Positive attitude	4	
Comparison to others	1	
Fear		1
Work Concerns		
Not working/work difficult		3
Family/Support		
Enjoy child care	1	
Professional support	1	

Illness Intrusiveness

This section is dedicated to the results of the first part of the Illness Intrusiveness Scale, where the study participants were asked to rate each of 13 life domains on the degree to which the effects of their trauma currently impede their pursuit of valued interests and activities along a 7 point scale (a rating of 1 meaning not very much and a rating of 7 meaning that the effects of the trauma interfere with the pursuit of interests and activities in that domain very much). Ratings for each life domain addressed in this scale are presented in Table 31, followed by sum across ratings of all 13 domains.

Table 31 Summary of Descriptive Statistics for 13 Categories of the Illness Intrusiveness Scale (49 Subjects)

Domain	Range	Score=1 N(%)	1st Quartile	Median	3rd Quartile
Work	1 - 7	15(30.6)	1	3	6
Active Recreation	1 - 7	17(34.7)	1	4	6
Passive Recreation	1 - 7	30(61.2)	1	1	3
Financial Situation	1 - 7	23(46.9)	1	2	3
Relationship with Spouse	1 - 7	30(61.2)	1	1	3
Sex Life	1 - 7	32(65.3)	1	1	4
Family Relations	1 - 7	32(65.3)	1	1	2
Other Social Relations	1 - 7	27(55.1)	1	1	3
Self Expression Self Improvement	1 - 7	25(51.0)	1	1	4
Religious Expression	1 - 6	41(87.3)	1	1	1
Community and Civic Involvement	1 - 7	36(73.5)	1	1	2
Health	1 - 7	17(34.7)	1	3	5
Diet	1 - 7	31(63.3)	1	1	2
Total Illness Intrusiveness Score	13-64		17	32	45

Table 31 illustrates that among the trauma survivors in this study, illness intrudes to varying degrees on the life domains addressed by the Illness Intrusiveness Scale. The domains which have the greatest degree of impact include active recreation, work, health, and financial situation (median category >1). Subjects' ratings reflected the least impact of the long-term effects of trauma within the life areas of religious expression (87.3% of

respondents provided a rating of 1) and community and civic involvement (73.5% of respondents provided a rating of 1).

Total Illness Intrusiveness Score

The ratings from each of the categories above were summed for each study participant resulting in a total Illness Intrusiveness score. This score has possible values of 13 to 91. A score of 13 indicates that the respondent believed that at the time of the study interview, long-term effects of his/her injury did not disrupt interests and/or activities in the 13 categories listed in the scale very much. The range of values of the Illness Intrusiveness score for trauma survivors was from 13 to 64. The median was 32 and the mean score was 32.8 +/- 16.34. The mode was 13 (14% of respondents) and the remainder of the 49 respondents had total values that were evenly distributed from 14 to 64.

Within the review of the literature, several factors were identified as having potential associations with long-term outcomes of trauma victims. Table 32 displays the results of tests of association between the outcome variable of Illness Intrusiveness (total score) with these factors identified in the literature, which were done in order to explore for factors which may influence Illness Intrusiveness in this population.

Table 32 Summary of Tests of Association Between Illness Intrusiveness and Other Significant Study Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits for r
Sex	ANOVA	0.16		
Age	Kruskal-Wallis	0.98	-0.12	-0.39 - 0.16
Mechanism of Injury	ANOVA	0.002*		
Hospital LOS	Kruskal-Wallis	0.96	0.18	-0.11 - 0.44
ICU LOS	ANOVA	0.51		
GCS	Kruskal-Wallis	0.14		
ISS	Kruskal-Wallis	0.51		
RTS	Chi-square	0.13		
Disposition	Kruskal-Wallis	0.07		
Marital Status	Kruskal-Wallis	0.11		
Number of Children	Kruskal-Wallis	0.24		
Caregiving Responsibility	Kruskal-Wallis	0.11		
Pre-Injury Employment	Kruskal-Wallis	0.66		
Current Employment	Kruskal-Wallis	0.16		
Change in Work Status	Kruskal-Wallis	0.04*		
Education	Kruskal-Wallis	0.90		
Litigation	Kruskal-Wallis	0.007*		
Life Satisfaction	Kruskal-Wallis	0.001*		
Health Status	Kruskal-Wallis	0.003*		

* Statistically significant at the 0.05 level of significance

There is no evidence of a statistically significant association between Illness Intrusiveness and sex, age, hospital and ICU LOS, GCS, ISS, RTS, disposition after hospital discharge, marital status, the number of children each subject has, whether or not subjects were primary caregivers of their children, pre-injury and current employment status, and education level. There is, however, evidence of an association between mechanism of injury and Illness Intrusiveness, with motor vehicle accidents being associated with a greater degree of Illness Intrusiveness than falls or other mechanisms of injury. As well, among the 33 individuals who reported a change in work status

(employment status, occupation, or number of hours worked per week) after their injury, whether or not one attributed this change to their injury is associated with the degree of Illness Intrusiveness reported (attributing the change to the injury was associated with a greater degree of Illness Intrusiveness). Involvement in litigation is associated with the degree of Illness Intrusiveness reported by study participants with those who were involved in litigation having higher total Illness Intrusiveness scores than those who were not involved in litigation. The total Illness Intrusiveness scores are also associated with the other primary outcome variables of LS and HS among study participants (a higher degree of Illness Intrusiveness is associated with lower ratings of LS and poorer ratings of global HS).

Perceived Control

This section contains the results of the second part of the Illness Intrusiveness Scale in which the phenomenon of perceived control was explored. Study participants were asked to rate each of the 13 life domains presented in the first part of the scale, in relation to the degree to which they felt they had control over these areas of life on a 7 point scale (a rating of 1 signifies the report of minimal control over that domain and a rating of 7 signifies a great deal of control over that area of life). Individual ratings for each life domain are presented in Table 33, followed by sum across ratings for all 13 domains. The total perceived control score is then cross-tabulated with the other study variables to identify potential associations.

**Table 33 Summary of Descriptive Statistics for Perceived Control Categories
(Illness Intrusiveness Scale Part II; 49 Subjects)**

Domain	Range	1st Quartile	Median	3rd Quartile	Score=7 N(%)
Work	1 - 7	3	5	7	17(34.7)
Active Recreation	1 - 7	4	6	7	21(42.9)
Passive Recreation	1 - 7	6	7	7	35(71.4)
Financial Situation	1 - 7	4	6	7	18(36.7)
Relationship with Spouse	1 - 7	7	7	7	38(77.6)
Sex Life	1 - 7	5	7	7	34(69.4)
Family Relations	1 - 7	6	7	7	32(65.3)
Other Social Relations	2 - 7	5	7	7	27(55.1)
Self Expression Self Improvement	2 - 7	6	7	7	28(57.1)
Religious Expression	3 - 7	7	7	7	44(89.8)
Community and Civic Involvement	1 - 7	6	7	7	36(73.5)
Health	1 - 7	4	6	7	21(42.9)
Diet	2 - 7	6	7	7	32(65.3)
Total Perceived Control Score	45 - 91	72	79	88	

Similarly to the first part of the Illness Intrusiveness Scale, reports of perceived control vary among the different life domains assessed by this scale. The life areas in which the study participants reported the greatest degree of control include religious expression (89.8% of respondents provided a rating of 7), relationship with spouse (77.6% provided a rating of 7), community and civic involvement (73.5% provided a rating of 7), and passive recreation (71.4% provided a rating of 7) (Table 33). The ratings reflect the least amount of perceived control for the life domains of work, active recreation, financial situation, and health (median category below 7).

Total Perceived Control Scores

The ratings from the 13 life domains outlined above were summed for each study participant, resulting in a total perceived control score. Similar to the total Illness Intrusiveness score, this score had total possible values from 13 to 91. A score of 91 indicates that an individual perceives that he/she has a great deal of control over all 13 life domains presented through this instrument. The total perceived control score among

study participants ranged from 45 to 91 with a median value of 79. The mode was 91 with 7 out of the 49 participants (14%) indicating their perception of a great deal of control over all 13 life domains.

Table 34 presents a summary of tests of association done between the total perceived control score and variables which were identified through the literature review as factors which potentially influence outcomes among trauma survivors.

Table 34 Summary of Tests of Association Between Perceived Control and Other Significant Study Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits (r)
Sex	ANOVA	0.03*		
Age	Kruskal-Wallis	0.62	0.15	-0.14, 0.41
Mechanism of Injury	Kruskal-Wallis	0.09		
Hospital LOS	Kruskal-Wallis	0.28	-0.02	-0.30, 0.26
ICU LOS	Chi-square	0.46	-0.26	-0.50, 0.02
GCS	Chi-square	0.39		
ISS	Chi-square	0.70		
Time Since Injury	Kruskal-Wallis	0.31	0.26	-0.03, 0.50
Marital Status	Kruskal-Wallis	0.19		
Number of Children	Kruskal-Wallis	0.10		
Caregiving Responsibility	Kruskal-Wallis	0.82		
Pre-Injury Employment	Chi-square	0.06		
Current Employment	ANOVA	0.06		
Change in Work Status	Chi-square	0.24		
Litigation	ANOVA	0.004*		
Pre-Injury Illness	Chi-square	0.73		
Life Satisfaction	Kruskal-Wallis	0.0002*		
Health Status	Kruskal-Wallis	0.01*		

* Statistically significant at the 0.05 level of significance

There is no evidence of a statistically significant association between perceived control and age, mechanism of injury, hospital and ICU LOS, GCS, ISS, time elapsed

between injury and study interview, marital status, the number of children participants had, whether or not subjects were primary caregivers of their children, pre-injury and current employment status, whether or not one attributed a change in work status to their injury, and reports of pre-injury illness (Table 34). Employment status, both pre-injury and current (those working reported higher perceived control scores), and mechanism of injury appeared from the raw data to be potentially associated with perceived control among this sample, however, these associations were not statistically significant.

Perceived control is associated with sex in this sample, with men reporting a greater degree of perceived control than women. As well, those who were involved in litigation at the time of the study interview provided lower ratings of perceived control than those who were not involved in litigation. LS is also associated with perceived control, whereby greater LS is associated with higher perceived control scores. Higher perceived control scores are also associated with better reports of overall HS.

Illness Intrusiveness by Perceived Control

There is an inverse relationship between Illness Intrusiveness and perceived control for trauma survivors in which the higher Illness Intrusiveness scores are associated with the lower perceived control scores and the lower Illness Intrusiveness scores are associated with the higher perceived control scores ($r = -0.70, -0.82 - -0.53$).

The Sickness Impact Profile

The results of the SIP, as part of the study instrument, are presented in this section. The descriptive statistics outlining the results of an assessment of each separate category of the SIP are presented in Table 35, along with physical, psychosocial, and total SIP scores. At the end of this section, these composite scores are compared with the other primary study variables to explore for potential associations.

Table 35 Summary of Descriptive Statistics for the Sickness Impact Profile and Sickness Impact Profile Subscale Scores (49 Subjects)

Category	Score=0 N(%)	1st Quartile	Median	3rd Quartile	Maximum	Range of Possible Scores
Sleep and Rest	20(40.8)	0	6.1	16.7	41.6	0-49.9
Emotional Behavior	24(49.0)	0	4.6	16.7	57.3	0-70.5
Body Care and Movement	22(44.9)	0	3.0	22.7	68.7	0-200.3
Home Maintenance	24(49.0)	0	4.4	14.2	49.3	0-66.8
Mobility	32(65.3)	0	0	8.1	24.2	0-71.9
Social Interaction	17(34.7)	0	12.3	35.2	100.6	0-145
Ambulation	20(40.8)	0	5.4	20.0	49.0	0-84.2
Alertness Behavior	20(40.8)	0	7.8	22.3	77.7	0-77.7
Communication	31(63.3)	0	0	8.3	51.1	0-72.5
Work	25(51.0)	0	0	20.3	38.5	0-51.5
Recreation and Pastimes	14(28.6)	0	12.6	19.2	29.4	0-42.2
Eating	36(73.5)	0	0	3.7	21.2	0-70.5
Physical Dimension	17(34.7)	0	4.35	12.93	32.18	0-100
Psychosocial Dimension	10(20.4)	1.86	9.57	25.62	69.73	0-100
Total SIP Score	7(14.3)	1.75	10.29	22.06	49.63	0-100

The first part of Table 35 above displays the scores for each of the 13 categories of the SIP. A score of 0 indicates that an individual did not respond to any of the statements reflecting an impact of sickness on that area of life. The categories with the least amount of ratings of 0 include recreation and pastimes and social interaction, indicating that these areas of life are most affected by sickness, including the long-term effects of trauma, for this sample of trauma survivors. The categories which contain the greatest proportion of scores of 0 include eating, mobility, and communication, indicating that these areas may be the least affected by sickness at one to two years post injury for trauma survivors.

The physical score of the SIP is lower than the psychosocial score of the SIP for this group of trauma survivors. The physical dimension of the SIP is positively correlated

with the psychosocial dimension ($r = 0.61, 0.39 - 0.76$). The total SIP scores indicate that only 7 out of 49 respondents did not respond to any of the statements reflecting impact of sickness on their lives.

Physical Dimension of SIP by Key Outcome Variables

Table 36 displays the comparisons of the physical dimension of the SIP to other key outcome variables. The physical score of the SIP is positively associated with Illness Intrusiveness. The data from Table 36 suggests an inverse relationship between the physical dimension score of the SIP and perceived control. Lower physical dimension scores are associated with a higher reported perceived control and higher physical dimension scores are associated with a lower degree of perceived control over specified life domains. In comparing ratings of LS and HS to the physical score of the SIP, for this sample of trauma survivors, there is no evidence to indicate an association between these variables.

Table 36 Summary of Comparisons of the Physical Dimension of the Sickness Impact Profile to Key Outcome Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits (r)
Illness Intrusiveness	Kruskal-Wallis	0.003*	0.40	0.14, 0.61
Perceived Control	Kruskal-Wallis	0.001*	-0.36	-0.59, -0.09
Life Satisfaction	Kruskal-Wallis	0.13		
Health Status	Kruskal-Wallis	0.07		

Psychosocial Dimension of SIP by Key Outcome Variables

Table 37 displays the comparison of the psychosocial score of the SIP to other key outcome variables. The psychosocial score from the SIP, for this group of trauma survivors, is associated with total Illness Intrusiveness scores, whereby the impact of sickness on psychosocial function is low among those relating a lower degree of Illness Intrusiveness and high among those relating a high degree of Illness Intrusiveness. The psychosocial dimension score of the SIP is inversely associated with perceived control with higher psychosocial scores being associated with a lower degree of perceived control

and lower psychosocial scores being associated with a greater degree of perceived control. Comparison of the psychosocial score from the SIP with individual ratings of LS among the 49 study participants reveals an association between these two variables. Lower psychosocial ratings are associated with greater LS and higher psychosocial ratings are associated with less satisfaction and enjoyment of life. Table 37 also provides evidence of a statistically significant association between the psychosocial score of the SIP and ratings of overall HS (higher psychosocial scores are associated with lower reports of HS).

Table 37 Summary of Comparisons of the Psychosocial Dimension of the Sickness Impact Profile to Key Outcome Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits (r)
Illness Intrusiveness	Kruskal-Wallis	<0.001*	0.71	0.53, 0.82
Perceived Control	Kruskal-Wallis	<0.001*	-0.56	-0.73, -0.33
Life Satisfaction	Kruskal-Wallis	<0.001*		
Health Status	Kruskal-Wallis	0.008*		

Total SIP Score by Key Outcome Variables

Table 38 displays the comparisons of the total SIP scores with other key outcome variables. There is a positive association between SIP scores and Illness Intrusiveness scores. It also appears that SIP scores which indicate a high degree of sickness impact on life domains are associated with a lower degree of perceived control of individuals. The data suggests that lower SIP scores are associated with a greater degree of LS and that higher SIP scores are associated with lower levels of LS. More favorable reports of HS are also associated with lower SIP scores and less favorable reports of HS are associated with higher SIP scores in this study sample.

Table 38 Summary of Comparisons of the Total Sickness Impact Profile Score to Key Outcome Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits (r)
Illness Intrusiveness	Kruskal-Wallis	<0.001*	0.72	0.55, 0.83
Perceived Control	Kruskal-Wallis	<0.001*	-0.62	-0.77, -0.41
Life Satisfaction	Kruskal-Wallis	<0.001*		
Health Status	Kruskal-Wallis	0.005*		

Total SIP Score by Demographic Variables

Table 39 below provides a summary of comparisons of the total SIP score to factors which were identified through a review of the literature to have potential associations with long-term outcomes of trauma survivors.

Table 39 Summary of Comparisons of the Sickness Impact Profile Total Score to Demographic Variables

Variable	Test of Association	p value	Correlation Coefficient (r)	Confidence Limits (r)
Sex	Kruskal-Wallis	0.05*		
Age	Kruskal-Wallis	0.20		
Injury Class	Kruskal-Wallis	0.92		
Mechanism of Injury	Kruskal-Wallis	0.15		
Hospital LOS			0.23	-0.05, 0.48
ICU LOS	Kruskal-Wallis	0.20		
GCS	Kruskal-Wallis	0.97		
ISS	Kruskal-Wallis	0.08		
RTS	Kruskal-Wallis	0.15		
Disposition	Kruskal-Wallis	0.06		
Time Since Injury			0.02	-0.26, 0.30
Marital Status	Kruskal-Wallis	0.38		
Number of Children	Kruskal-Wallis	1.00		
Caregiving Responsibility	Kruskal-Wallis	0.08		
Pre-Injury Employment	Kruskal-Wallis	0.003*		
Current Employment	Kruskal-Wallis	0.0004*		
Change in Work Status	Kruskal-Wallis	0.24		
Education	Kruskal-Wallis	0.17		
Litigation	Kruskal-Wallis	0.008*		
Pre-Injury Illness	Kruskal-Wallis	0.36		

* Statistically significant at the 0.05 level of significance

From Table 39 above, it is evident that for this study sample there is no evidence of a statistically significant association between SIP scores and age, injury class (the number of participants with penetrating or burn injuries is too small to detect an association in this study), mechanism of injury, hospital and ICU LOS, GCS, ISS, RTS, disposition, the amount of time between injury and study interview, marital status, the number of children each subject has, whether or not they are primary caregivers of their children, whether or not one attributed a change in work status to their injury, education, and pre-injury illness. The raw data, however, indicated potential associations between ISS and total SIP score (higher ISS being associated with higher SIP scores), between disposition after hospital discharge and total SIP scores (those discharged home versus requiring home care or admission to a rehabilitation or active treatment facility had higher SIP scores), and between caregiving responsibility and total SIP scores (those reporting primary caregiving responsibilities of their children had lower SIP scores).

There is an association between the total SIP scores and sex, where men appear to have lower total scores than women. The results of the above comparisons also indicate that pre-injury employment status is associated with SIP scores, with those participants who reported working prior to their injury reporting a lesser degree of sickness impact on their lives than those who were not working. Current employment is also associated with a lesser degree of the impact of sickness on the lives of study participants. The data also suggests an association between involvement in litigation and total SIP scores. Higher SIP scores are associated with involvement in litigation.

Additional Health Related Concerns

Upon completion of the study interview, all respondents were asked if they had any additional concerns or comments, relating to their health, that were not adequately addressed by the interview guide. Most of the respondents framed their answers within the context of their "biggest concern". Some of the responses were not brought out by the questionnaire, however, many of the answers were repeating, or re-emphasizing what had

been discussed throughout the interview. This question allowed the study participants to explain their concerns in their own words. In similar fashion to the way the results to the above open-ended questions were presented, the responses to this question are presented according to 7 main themes of limitations in activities and interests, work/economic concerns, physical symptoms/disease, attitude/benefits of injury, support, fitness, and progression of recovery (Table 40).

Limitations in Activities and Interests

The category involving limitations in activities and interests (i.e., sports, recreation, hobbies) was the area most frequently referred to by study participants in discussing their overall concerns at approximately one to two years post-injury. Many respondents stated that their present state of health interfered with interests and activities that they value and enjoy (n=29) and several others related that their health affects their social relationships (n=7). Nine of the respondents who had concerns about their limitations stated that over time, one learns to accept or overcome their disabilities.

Work/Economic Concerns

The category encompassing work-related concerns ties in closely with concerns regarding limitations discussed above. Many respondents indicated that the long-term effects of their injury affected their work life to some degree, causing job changes for some and preventing work entirely for others. Three individuals commented about the amount of time it took to return to work, with one person returning after 3 months, one after 4 months, and one commented that despite an early return to work, it took about a year to function well at work. Financial concerns as a result of dealing with the consequences of the accident were discussed by some participants, with one individual talking about how difficult it was to apply for funding to carry him through the rehabilitation phase until he could get a job.

Physical Symptoms/Disease

Illness or disease, not related to their injury, caused eight individuals great concern in relation to their overall HS (i.e., heart disease, diabetes, Amyotrophic Lateral Sclerosis, arthritis). Arthritis caused from injuries and being required to take medications were significant concerns for several individuals who were interviewed. Many of the respondents described specific symptoms as causing concern over their health, with pain (n=17) and decreased mobility (n=16) as two of the most frequently related symptoms. Two people indicated that being dependent on ambulatory aids posed great concern for them in relation to their health. Several individuals stated that activities and work were found to be much more taxing, or took much longer to accomplish, since their injury (n=7). A few study participants explained that the physical healing is the easy part, and that the mental or emotional healing is what is difficult and takes the most time, with additional concerns of depression, mood swings, and anxiety from some.

Attitude/Benefits of Injury

Having a positive attitude and being motivated was often discussed as an important aspect to a speedy recovery by respondents (n=9). Many individuals indicated that they felt very lucky to have lived or recovered to the degree they did, and some stated that they enjoy life more since their injury. Several individuals talked about how the trauma that they were involved in provided some benefits as well as difficult times (n=7). Some of the comments included that they had become more spiritual, more sensitive to others' hardships, made family and friends more important, improved their relationship with their spouse, put life into perspective, and made one thankful for what they are capable of overcoming. Some study participants, however, also indicated that problems from their injuries caused their motivation and self-confidence to decrease and their outlook on life to change. A couple of participants commented that they were not willing to accept the new limitations imposed by their injuries. Fear of re-injury or exacerbating current problems caused some individuals to become very cautious. Feelings of anger and frustration

regarding the injury and recovery process were mentioned. Some people stated that the accident made them more aware of their own mortality, however, others said that the fact that they survived such a serious injury made them feel indestructible. One person indicated that the accident does not necessarily make you change your high risk behavior.

Support

Some of the study participants found family, friends, and health professionals or programs very supportive, whereas others related a lack of adequate support for the transition from hospital to home and in receiving appropriate help after discharge from the hospital. One individual felt that his involvement in litigation made it even more difficult to get the help he needed. Some individuals expressed feelings of being a burden on others and were tired of being helped.

Fitness

Five study participants explained the importance of fitness in overcoming the effects of their injuries and speeding their recovery.

Progression of Recovery

Comments regarding the time required for recovery from injuries ranged from no long-term consequences of the injury at all for 6 individuals to statements that some individuals were still recovering at the time of the interview (one of these at 2 years post injury).

Table 40 Additional Health Related Concerns

Specific Comment/Concern	N Positive	N Negative
Limitations in Interests and Activities		
Health interferes with interests/activities		31
Health affects socializing		7
Limited in food preparation		1
Learn to overcome disabilities	9	
Work/Economic Concerns		
Injury affects current work life		10
Not working due to health		5
Required to change jobs post-injury		2
Financial concerns		3
Physical Symptoms/Disease		
Illness not injury-related		8
Arthritis from injuries		2
Required to take medication		5
Aging		1
Difficulty recovering from colds		1
Complication from hospital treatment		1
Specific Symptoms		
Pain		17
Decreased mobility		16
Dependent on ambulatory aids		2
Memory		6
Concentration		3
Balance		4
Temper		2
Dizziness		1
Reasoning		1
Eyesight		6
Hearing		2
Smell		2
Taste		1
Speech		2
Loud noises		2
Light		1
Sleeping		3
Back problems		3
Weakness		4
Fatigue		2
Restlessness		1
Circulation		1

Table 40 Additional Health Related Concerns (continued)

Specific Comment/Concern	N Positive	N Negative
Activities more taxing		7
Feel older		1
Difficulty with emotional healing/Mental distress		4
Depression		2
Mood swings		1
Anxiety		1
Difficult dealing with life in general		1
Loss of control		1
Difficulty accepting changes		1
Flashbacks		1
Attitude/Benefits of Injury		
Positive attitude/motivation	9	
Feel lucky	6	
Enjoy life more since injury	2	
Life good but not like pre-injury		1
Injury provided some benefits	7	
Decreased motivation		3
Changed outlook on life		5
Everything changed		4
Will not accept limitations		2
Decreased self-confidence		3
Fear		7
Anger		3
Frustration		1
Aware of own mortality		1
Indestructible attitude		2
Maintain high risk behavior		1
Support		
Family/friends supportive	1	
Difficult transition from hospital to home		1
Rehabilitation programs helpful	3	
Alternative medicine helpful	2	
Difficulty getting counseling		3
Tired of being helped		3
Fitness	5	
Progression of Recovery		
No long-term effects of injury	6	
4-8 months to recover	4	
Recovery for 8 months then no improvement		1
1 1/2 years for physical recovery		1
Still recovering		3

CHAPTER 4

DISCUSSION

Summary and Implications of Findings

Characteristics of Study Population

The demographics and injury descriptions in this study reflect the trauma population after study criteria were employed, therefore, the results are not intended to be representative of all trauma survivors. Severe head and spinal cord injured individuals and those who died were not included in the description of this sample of trauma survivors. The results may have been much different with inclusion of these individuals, therefore generalizability of the study is limited. Generalizability of the study findings is limited due to the exclusion of these individuals along with a 65% response rate among those who were eligible.

The median age of this study sample was 33 years and almost 70% of respondents were under the age of 45 years. Approximately 2/3 of all participants were males. This is very similar to other studies in the literature in which the typical trauma victim is a younger male with the risk for males being 2.5 times that of females (Weigelt & McCormack, 1994). Several sources report that 60% - 75% of their study populations were males and that most individuals were between 15 and 44, or 15 and 55, years of age (Champion, et al., 1989; Regional Trauma Services Coordinators, 1993-1994; Injury Data Coordinator, 1993).

Falls accounted for the majority of injuries in this study (40.8%) with motor vehicle accidents responsible for 38.8% of injuries. According to the literature, the leading source of injury is mechanical energy, with motor vehicle accidents providing the single biggest contribution to mechanism of injury (Baker, et al., 1992; Robertson & Redmond, 1991; Robertson, 1992). The Major Trauma Outcome Study reported that 49.1% of trauma victims were in motor vehicle related injuries, with violence related injuries accounting for 19.5% of injuries and falls accounting for 16.5% (Champion, et al.,

1990). However, these statistics describe all injury victims, including those who did not survive, whereas the mechanism of injury statistics for this study reflects statistics compiled following exclusion of those who did not meet entrance criteria (i.e., death, spinal cord injury, severe head injury). The Alberta Data Report on Injury Deaths and Hospitalizations indicates that the most common cause of hospitalization was falls followed by motor vehicle accidents, however, statistics from Alberta which include those who died reveal the most common mechanism of injury is motor vehicle accidents followed by falls (Injury Data Coordinator, 1993; Regional Trauma Services Coordinators, 1993-1994). Interestingly, the rank order of mechanism of injury for males and females in this study differed, with falls accounting for the most female injuries followed by moving vehicle injuries (includes motor vehicle, pedestrian, and bicycle accidents), and moving vehicle injuries accounting for the most male injuries, followed by falls. Gender differences in relation to mechanism of injury were not noted in the previous review of the literature.

Most individuals in this study did not require ICU care and the median hospital LOS was 10 days. The majority of study participants, however, were victims of major trauma as 65.3% had an ISS of 16 or greater. Alberta statistics reveal that 59% of all trauma victims (including those who died) were discharged home (Regional Trauma Services Coordinators, 1993-1994). This study revealed that 79.6% of trauma victims who met study entrance criteria were discharged home, versus being discharged home with home care or being transferred to a rehabilitation or other active treatment facility.

Employment status and quality of working life post injury are significant concerns for this sample of trauma survivors. A 5 year follow-up study reported that 79% of injured patients admitted to ICU eventually return to work, however, 11% changed occupations and 35% reported significant problems at work (Frutiger, et al., 1991). Another follow-up study of severely injured trauma patients reported that 95% were employed pre-injury as compared to 55% post-injury (Morris, et al., 1991). In contrast,

this study revealed that only 70% of participants were working pre-injury, which may be a reflection of the economic state in Alberta and current high unemployment rates. At one to two years post injury only 51% of individuals reported that they were currently working, with 25% of those working pre-injury no longer employed post-injury. The degree of unemployment increased with increasing age, and interestingly, more women than men were unemployed post injury despite no gender differences pre-injury with respect to employment status. Gender differences in return to work had not previously been reported. Sixty-seven percent of study participants stated that they changed their occupation, employment status or number of hours worked per week after their injury, and 42% of those who reported a change attributed this change in work status to their injury. These statistics indicate that employment related concerns are present among a significant proportion of this study sample.

It was found that 22.4% of study participants were involved in litigation at the time of study interview. Involvement in litigation, in relation to trauma outcomes, had not been explored in the literature. A significant proportion of individuals are involved in litigation proceedings, therefore, involvement in litigation is an important intervening variable to explore in relation to its effect on trauma outcomes.

Life Satisfaction

In general, trauma survivors in this study rated their satisfaction with life quite high. Twenty-four out of 49 (49%) of the sample provided a rating of a lot of satisfaction and enjoyment of life. Interestingly, there were more men who provided this response than women. Sex differences in LS ratings had not been reported in the literature. Twenty out of 49 respondents (40.8%) stated they had fairly much satisfaction and enjoyment of life, resulting in the vast majority of participants providing one of the top two responses. Only 4/49 or 8.2% provided a rating of very little satisfaction and enjoyment and 1/49 or 2% stated they felt they had absolutely no satisfaction or enjoyment from life. One group of investigators used the same LS instrument to assess LS in 3

groups of individuals; head and neck cancer patients, 3-10 months post-injury orthopedic patients, and healthy individuals (Kreitler, et al., 1993). The mean age of each of these groups was higher than the mean age of the trauma survivors, but otherwise demographic characteristics were similar. This study found that LS ratings did not differ between study groups, with 54.55% of the cancer group, 57.94% of the orthopedic group, and 58.18% of the healthy group providing one of the top 2 ratings of LS, versus 89.8% of this sample of trauma survivors. The trauma survivors may have provided higher ratings of LS because the age of the trauma survivors was lower than the cancer, orthopedic, or healthy groups of individuals discussed above. It has been suggested that a certain level of LS is necessary for daily physical and psychological functioning, which may also explain, in part, the high LS ratings in this sample of trauma survivors (Kreitler, et al., 1993).

The only objective measurements associated with LS among this study sample include sex, as previously discussed, and mechanism of injury, with moving vehicle and violence related injuries being associated with lower ratings of LS than injuries from falls. This may appear to be due to the severity of injury being greater among those who suffered moving vehicle accidents than those who suffered falls, however, LS was not associated with severity of injury indices (i.e., ISS, RTS) in this study. Injury severity measures (i.e., ISS, RTS) had been previously demonstrated to predict mortality but had not been explored in relation to other outcome variables such as LS (Schuster, 1992; Suter, et al., 1994). There is minimal data in the literature with respect to the impact of age on psychosocial, LS, or QOL outcomes (Jaffin, et al., 1993), and pre-existing illness has been associated with mortality but there is no data to suggest that it predicts long-term outcomes or psychosocial sequelae (Milzman, et al., 1993). This study did not detect an association between LS and age or pre-injury illness.

The referents that this sample of trauma survivors used in rating their satisfaction with life include the major areas of attitudes, limitations, physical/emotional symptoms, personal/social life, economic/job situation, and physical fitness. The most frequent

referent used by individuals who provided a high rating of LS was related to positive attitudes. The lack of limitations in interests and activities and personal factors (i.e., family life, spiritual life, and support from friends) were also frequently described as the reasons for high ratings of LS. Other referents included fulfillment at work, lack of poverty, and physically fitness. Negative LS ratings were often attributed by study participants to physical and emotional symptoms and to limitations in valued interests and activities. Other referents reported by individuals who felt that their LS was not as good as it should be include fear of re-injury and feeling changed by the accident, poor social support, and employment or money concerns.

These referents used in providing ratings of LS seem to overlap considerably with the general components of QOL, which include personal safety, health, social participation, access to goods and services, housing, aspects of the physical environment, quality of working life, employment, individual development through learning, time and leisure use, and justice. LS has been described as one of a set of constructs defining QOL, involving the perceptual component (Kreitler, et al., 1993).

The findings with respect to LS referents are somewhat similar to a study of LS among spinal cord injured individuals, which found that high satisfaction ratings were accorded to family relationships, spiritual life, and daily living tasks whereas low LS ratings were associated with money matters, sex life, and employment (Fuhrer, et al., 1992). Psychological stress, well-being, and fear of unemployment have also been associated with LS in other studies (Ware, 1992) (Fylkesnes & Forde, 1992). Pre-injury and current employment status were not associated with ratings of LS among study participants, however, several individuals discussed employment as a reason for their LS ratings in their responses to the open-ended questions which explored LS referents. Income, education, leisure satisfaction, self esteem, bereavement, marital status have been associated with LS but vary in degree of association between studies (Baiyewu & Jegede, 1992)(Kinney & Coyle, 1992; Kreitler, et al., 1993). Although many of these factors were

discussed as referents used in reporting LS, associations between LS and marital status, and LS and education level, were not statistically significant.

Interestingly, the referents that the study participants described were primarily subjective factors. This study indicates objective measurements such as severity of illness indices, hospital and ICU LOS, injury class, disposition, etc., are not well correlated with LS but subjective factors, as discussed above, appear to be the primary determinants.

In summary, LS ratings among study participants appear to be higher than ratings previously reported by both healthy and sick populations. The only objective measures that LS appears to be associated with include sex and mechanism of injury. The primary referents that subjects describe with respect to their LS ratings include attitudes, limitations, physical/emotional symptoms, personal/social life, economic/job situation, and physical fitness. This study seems to support the assertion that LS is not dependent on any one or more specific factors but rather is a function of individual situation, which dictates the degree of contribution of any one domain to overall LS (Kreitler, et al., 1993).

Health Status

Global Health Item

The vast majority of study participants (85.7%) rated their health from good to excellent (excellent: 16.3%, very good: 34.7%, good: 34.7%). Only 12.2% rated their HS as fair and 2% as poor. Canada's Health Promotion Survey reported the responses of the general public on the same global HS questions and found that 87% of persons surveyed reported that they are in excellent (26%), very good (35%), or good (26%) health. Only 10% rated their HS as fair and 3% as poor (Health and Welfare Canada, 1993). These findings are remarkably similar to the findings of HS ratings among this sample of trauma survivors, with approximately the same amount of ratings of excellent, very good, or good between the 2 groups. The trauma survivors provided less ratings of excellent health, though, and more ratings of good health.

A study conducted in Norway on the general population found that 28.3% of men and 27.4% of women rated their health as excellent, 52.8% of men and 53.2% of women rated their health as good, 16.1% of men and 16.6% of women rated their health as fair, and 2.9% of men and 2.8% of women rated their health as poor. This compares very closely to the Canadian data cited above, as well as this study, with a slightly lower proportion of ratings of excellent among trauma survivors. It appears that the self-reported HS among trauma survivors is only slightly lower than the general population.

Several studies have shown poor reports of HS to increase with increasing age (Fylkesnes & Forde, 1991; Fylkesnes & Forde, 1992; Health and Welfare Canada, 1993). In this study age was not associated with ratings of health, however, similar to the association with LS ratings, male participants rated their health higher than female participants. HS had generally not been shown to be associated with sex in the literature, although one study showed that for individuals aged 45 to 54, women reported a significantly lower HS than men (Fylkesnes & Forde, 1991).

Similar to the association with LS ratings, mechanism of injury was related to self reports of HS, with those individuals who suffered moving vehicle or violence related injuries reporting lower levels of health than those whose injuries were caused by falls. This association may be related to the lack of control, or inability to escape the event, that one may feel when involved in moving vehicle or violence related accidents (Waites, 1993). Traumas caused by human actions (i.e., stabbings, motor vehicle collision from drunk driving) have been purported to elicit more severe responses than traumas of natural origin (i.e., caused by natural disasters) (Tanaka, 1988).

The only other factor identified as having a potential association with HS from this study was RTS, with those with lower RTS reporting lower levels of health. Therefore, severity of injury may play a role in self reports of HS. This may tie in with the association with mechanism of injury, whereby more severe injuries (i.e., moving vehicle or violence related injuries) may be associated with lower reports of health than less severe

injuries (i.e., falls). It is interesting that a severity of injury measure would be associated with HS but not LS among study participants.

The prevalence of pre-existing illness in the trauma population has been reported in the literature to be 14-16% (Milzman, et al., 1993), however, in this study, 41% of participants reported some type of pre-injury illness ranging in severity from previous surgery or mild medical condition (i.e., asthma) to Amyotrophic Lateral Sclerosis. The low proportion of pre-injury illness in other studies may be due to strict criteria for defining illness prior to injury. The incidence of pre-injury illness increased with age in this study sample.

The referents that study participants used most frequently in providing a favorable HS rating include feeling well physically and emotionally and being active or physically fit. Other referents used by participants who had high HS ratings included having a positive attitude, not being limited in activities, and having family or professional support. Lower HS ratings (HS ratings that were lower than what the individual felt they should have) were attributed frequently to physical or mental symptoms, disease, or disability. Being limited with respect to involvement in interests and activities, feeling physically unfit, having employment concerns, and fear of re-injury were also frequently reported as reasons for lower HS ratings.

Reports of worse health have been previously reported to be almost entirely related to the physical experience of adverse health (i.e., symptoms, medication use, past surgery) whereas better health has been related to the presence or absence of illness to a limited degree (Smith, et al., 1994). These investigators suggest that if one is ill, that individual defines their health by medical related concerns, and others define their health by conditions which extend beyond the traditionally defined dimensions. The study findings among trauma survivors are generally concordant with the above findings, however, this study found that the division between referents for ill and good health are not as distinct as indicated above. This study supports the notion that the global health

item may be interpreted in a variety of ways and the tendency to use a particular referent may not be distributed randomly in the population (Krause & Jay, 1994).

Some studies have shown that the referents used by individuals in responding to the global HS item are primarily physical health factors, and to a much lesser extent, psychological and behavioral factors (Krause & Jay, 1994). Another study found that somatic symptoms and disease connected to the musculoskeletal system was the best predictor of self-evaluated health but that leisure time activities and the psychosocial element have direct, strong effects, intoning the complexity of this construct (Fylkesnes & Forde, 1991). This study revealed that although physical functioning plays a large role in self-rated health, especially when the health ratings are poor, involvement in interests and activities, attitudes, and social support also are significant factors that trauma survivors consider in assessing their HS.

Sickness Impact Profile

Another assessment of HS that was included in the study instrument was the SIP. The median total SIP score for this sample of trauma survivors was 10.29. One study conducted with a total of 2527 respondents with varying disease states demonstrated a mean SIP score of 10.8, ranging from 4.8 for those with back or neck pain to 19.9 for those with spinal cord injuries (De Bruin, et al., 1994). Subgroups of individuals with a diagnosis of ankylosing spondylitis (mean SIP score 9.9) and head injuries (mean SIP score 10.5) compared favorably with the scores from this sample of trauma survivors.

The results of the SIP assessment indicate that among this sample of trauma survivors, the greatest impact of sickness (including long-term effects of trauma) occurs in the life areas of recreation and pastimes and social interaction. This is congruent with the referents participants used in reporting HS, which emphasized limitations in activities and interests and social support. The category scores in the areas of eating, mobility, and communication demonstrated the least impact of sickness among study participants. The physical score of the SIP was lower than the psychosocial score, indicating that sickness

has a greater impact on dimensions of life relating to psychosocial functioning than physical functioning at one to two years post injury. Physical adjustment has been shown in previous studies to occur in the first year but psychological adjustment has been reported to continue beyond one year (Neff & Kidd, 1993; Strohmyer, et al., 1993). The physical measure of the SIP was positively correlated with the psychosocial measure indicating that those who reported a high degree of sickness impact on physical functioning also reported a high degree of sickness impact on psychosocial functioning, and low impact in physical functioning was associated with low impact in psychosocial functioning. These results indicate that physical functioning, although demonstrating less impact than psychosocial functioning, continues to be a concern for this sample of trauma survivors.

Interestingly, the physical dimension score of the SIP is positively correlated with the Illness Intrusiveness scores and negatively associated with the perceived control scores of study participants. Therefore, those reporting a high degree of Illness Intrusiveness also scored highly with respect to the impact of sickness on their life, and reported low perceived control scores. There were no statistically significant associations between the physical score of the SIP and LS or HS among this sample of trauma survivors. The impact of sickness on life domains reflecting physical functioning does not appear to predict overall LS or HS ratings.

The psychosocial dimension of the SIP was, however, not only associated positively with the Illness Intrusiveness score and negatively with the perceived control score, as with the physical score, but was also negatively associated with the ratings of LS and HS among study participants. Therefore, interestingly, reports of LS and HS may be associated with psychosocial functioning but not necessarily physical functioning.

As well, the total SIP score was associated positively with the Illness Intrusiveness scores, negatively with the perceived control scores, and was negatively associated with the ratings of LS and HS among study participants. Therefore, the overall impact of

sickness on physical and psychosocial functioning was associated with LS and HS ratings among study participants. The total SIP score was also associated with sex, whereby male subjects scored lower on the SIP than female subjects. This is consistent with the associations identified between sex and LS and HS identified earlier. Pre-injury and current employment status were associated with SIP scores whereby those who reported currently working relayed a lesser degree of sickness impact on their lives (lower total scores). This again emphasizes that at one to two years post injury there are significant long-term injury effects which cause employment related concerns for some individuals. Higher SIP scores were also associated with current involvement in litigation. This association may be present because those who perceived the greatest degree of sickness impact are the individuals motivated to initiate litigation proceedings, or possibly because once one is involved in litigation, one's perception of the degree of sickness impact is heightened.

Potential associations were identified between total SIP scores and ISS (higher ISS being associated with higher SIP scores). Injury severity appears to have potential associations with HS, but not with ratings of LS, among participants. Potential associations were also identified between total SIP scores and disposition after hospital discharge (those who were discharged home having the lowest SIP scores in comparison to those who required home care or were discharged to an active treatment or rehabilitation facility) and between total SIP scores and caregiving responsibility (those reporting primary caregiving responsibilities of their children having lower SIP scores). These associations were not statistically significant, however, the sample size may have been too small to detect a difference.

At the completion of the study interview, subjects were asked if they had any additional health concerns not brought out by the interview questionnaire. Some of the comments brought forth new information, however, most of the individuals provided comments which re-emphasized important aspects of their ability to function and enjoy life

post injury. The majority of individuals in this study commented that their health interferes with interests and activities that they value. Many individuals took the opportunity to discuss specific physical symptoms that were not adequately addressed by the questionnaire (pain and decreased mobility being the 2 most common symptoms discussed). Many individuals discussed how the injury continues to affect their work life and financial situation. The key role of personal attitudes was frequently discussed in relation to HS. Social and professional support was re-emphasized by many subjects as necessary for good health, and physical fitness was mentioned again by some individuals. Some participants also commented on the time required for recovery, which ranged from no long-term effects at all, to comments that recovery was still occurring at one to two years post-injury. Previous studies have shown that most individuals return to pre-admission levels of functional status by 6 months to 1 year post injury (Holbrook, et al., 1994; Ridley & Wallace, 1990; Strohmyer, et al., 1993; Zaren & Hedstrand, 1987). These comments reinforce the multidimensional nature of the concept of self-reported HS and that physical symptoms are a significant concern, especially when they interfere with involvement in valued interests and activities.

In summary, global health ratings among trauma survivors appear to be only slightly below that of the general population, and are associated with sex, mechanism of injury, and RTS. The referents that trauma survivors use in providing positive HS ratings include feeling well physically and emotionally, positive attitudes, lack of limitations, and social support. Negative reports of health were attributed to physical symptoms, limitations in interests and activities, being physically unfit, employment related concerns, and fear of re-injury. Poor health reports appear to be more closely related to reports of ill health and favorable health reports reflect more non-traditional dimensions of health, however, there is a great deal of overlap in the dimensions of health reflected in good and less favorable ratings. The SIP revealed that the greatest impact of sickness occurred in the areas of recreation and pastimes and social interaction for trauma survivors. Impact

was most pronounced in the psychosocial areas of function, however, physical functioning appears to remain a significant concern for trauma survivors. The SIP total scores were associated with LS and HS ratings, Illness Intrusiveness and perceived control scores, sex, employment status, litigation, ISS, disposition and caregiving responsibility of participants.

Relationship Between Life Satisfaction and Health Status

Many studies have concluded that LS is not necessarily correlated with health, but that the difference between the 2 constructs is the domains that individuals refer to in providing their ratings of health and LS (Fuhrer, et al., 1992; Kinney & Coyle, 1992; Kreitler, et al., 1993). In this study, however, LS and self reported HS were associated. The responses to open-ended questions exploring the referents used in ratings of LS and HS reveal many overlapping areas. The difference seems to be the rank order of these categories rather than differences in the categories themselves. LS referents were primarily centered on the categories of attitudes and limitations whereas HS referents were more frequently associated with physical symptoms, especially in relation to reports of ill health.

Illness Intrusiveness and Perceived Control

Illness Intrusiveness

There were 14% of respondents who had total Illness Intrusiveness Scores of 13 (lowest possible score), however the remainder of the participants' scores indicated that the effects of the injury they sustained currently intrudes on interests and activities in a variety of life domains to some degree. The mean total Illness Intrusiveness score for trauma survivors in this study was 32.8 +/- 16.34. This is slightly lower than scores that have been reported in assessments of chronically ill populations; 42.6 +/- 14.56 for multiple sclerosis, 37.9 +/- 16.87 for rheumatoid arthritis, and 38.8 +/- 16.83 for individuals with end-stage renal disease (Devins, Edworthy, Seland, Klein, Paul, & Mandin, 1993b). A study comparing Illness Intrusiveness in patients with and without restless sleep, among a combined sample of individuals with chronic disease, found a mean

total Illness Intrusiveness score of 44 +/- 16.64 for those with restless sleep and 35.1 +/- 14.72 for those without restless sleep (rheumatoid arthritis: 41.8 +/- 17.40 vs 29.6 +/- 12.93, end-stage renal disease: 43.8 +/- 16.41 vs 32.5 +/- 15.31, multiple sclerosis: 47.5 +/- 15.49 vs 40.3 +/- 13.06) (Devins, Edworthy, Paul, Mandin, Seland, Klein, et al., 1993a). Another study found that among a group of individuals with end-stage renal disease, Illness Intrusiveness scores were 28.4 +/- 12.78 for individuals who did not experience headaches or muscle cramps and up to 46.9 +/- 10.10 for those who experiences both headaches and muscle cramps at both assessment intervals (Devins, Armstrong, Mandin, Paul, Hons, Burgess, et al., 1990). Illness Intrusiveness was also shown to increase with increasing degree of disability among a sample of rheumatoid arthritis patients (mean Illness Intrusiveness score of 30.3 +/- 12.75 for mild disability to 53.6 +/- 16.75 for severe disability) (Devins, Edworthy, Guthrie, & Martin, 1992). These investigators also found that Illness Intrusiveness is an underlying determinant of the psychosocial impact of chronic illness. It appears that the degree of Illness Intrusiveness among this sample of trauma survivors is slightly less than the degree of Illness Intrusiveness reported in chronically ill populations, and compares most favorably to those with only mild disability.

The domains of the Illness Intrusiveness Scale in which the greatest degree of intrusiveness was demonstrated among this sample of trauma survivors include active recreation, work, health, and financial situation. This again is consistent with the domains identified as important in the discussion of referents used in rating LS and HS. Subjects' ratings of Illness Intrusiveness reflected the least impact of the long-term effects of trauma within the life areas of religious expression and community and civic involvement.

Total Illness Intrusiveness scores were associated with mechanism of injury in this study, with individuals whose injuries were attributable to motor vehicle accidents providing the highest ratings of Illness Intrusiveness. This is consistent with associations between mechanism of injury and ratings of LS and HS. As well, those individuals who

attributed a change in work status (occupation, employment status, or number of hours worked per week) to their injury also provided higher ratings of Illness Intrusiveness than those who did not attribute this change to their injury. Therefore, those who have had a significant employment related change due to their injury feel that the long-term effects of their injury intrude on valued interests and activities to a great extent. Involvement in litigation was also associated with higher total Illness Intrusiveness scores among study participants. Again, those who feel that the effects of their injury significantly intrude on their lives may be more motivated to initiate litigation proceedings, or, involvement in litigation may alternatively heighten one's perception of the degree to which the long-term consequences of injury intrude on their lives. Total Illness Intrusiveness scores were also negatively associated with the other primary outcome variables of LS and HS. This is consistent with other study results whereby limitation or impedance of valued interests and activities impact the ratings of LS and HS.

In summary, the degree of Illness Intrusiveness, with respect to the long-term effects of trauma 1 to 2 years post-injury, is slightly less than the degree of Illness Intrusiveness for those with chronic diseases reported in the literature. The domains which reflect the greatest degree of intrusiveness for trauma survivors include active recreation, work, health, and financial situation. Total Illness Intrusiveness scores were associated with mechanism of injury, whether a change in work status was attributable to injury, litigation, and ratings of LS and HS among this sample of trauma survivors.

Perceived Control

Study participants reported the greatest degree of perceived control over the life areas of religious expression, relationship with spouse, community and civic involvement, and passive recreation. Subjects' ratings indicated that they felt the least control over the life domains of work, active recreation, financial situation, and health. These areas are consistent with the major areas identified as referents in ratings of LS and HS. Fourteen percent of the participants provided the highest possible perceived control score,

indicating a great degree of control over all life domains specified, however, the remainder of individuals expressed some degree of loss of control through lower total perceived control scores.

The total perceived control scores among subjects were associated with sex (men reported a higher degree of control than women), litigation (those involved in litigation provided lower total perceived control scores), LS (greater LS was associated with higher perceived control), and HS (higher perceived control scores were associated with more favorable HS ratings). The association between sex and perceived control is consistent with the associations between sex and ratings of LS and HS. Perception of control over the major domains in one's life may be an integral part of the concepts of LS and HS among trauma survivors.

There was an inverse relationship between total Illness Intrusiveness and perceived control scores where the greater the degree of Illness Intrusiveness, the lower the perception of control, and the less the degree of Illness Intrusiveness, the greater the perception of control over a variety of specified life domains. Studies investigating Illness Intrusiveness in end stage renal disease patients have also found a strong correlation between perceived control and the intrusiveness of disease and its treatment (Devins, et al., 1983-84).

In summary, the domains in which trauma survivors reported the least degree of control include work, active recreation, financial situation, and health. Perceived control was identified as having potential associations with sex, involvement in litigation, and ratings of LS and HS. There was an inverse relationship identified between Illness Intrusiveness and perceived control among study participants.

Conclusions and Recommendations

Summary of Key Findings - Hypotheses Generated

The major findings of this study center around the main outcome variables of LS, HS, Illness Intrusiveness, and perceived control. Global ratings of LS and HS revealed

that trauma survivors provided LS ratings which were slightly higher than previously reported sick and health populations and provided HS ratings which were only slightly below the general population. The intrusiveness of illness (i.e., the long-term effects of trauma) was slightly lower than the intrusiveness of illness described by victims of chronic illness presented in the literature. Sex was associated with ratings of LS and HS, as well as SIP scores and perceived control, with males providing more favorable ratings than females. Mechanism of injury was associated with LS, HS, and Illness Intrusiveness, with individuals who sustained moving vehicle or violence related injuries reporting less favorable ratings or scores than those who had sustained a fall. Injury severity was only related to the outcome variables in 2 cases; RTS were associated with global health ratings and ISS were associated with the total SIP scores. Interestingly, involvement in litigation at the time of study interview was associated with the SIP scores, Illness Intrusiveness, and perceived control. Employment issues were related only to SIP scores and Illness Intrusiveness. The rest of the demographic and objective measures were not associated with any of the primary outcome variables.

The major outcome variables were all associated with each other. LS ratings were associated with HS ratings. As well, SIP scores were associated with LS, HS, Illness Intrusiveness, and perceived control. Illness Intrusiveness was associated with LS, HS, SIP scores, and perceived control. Perceived control was associated with LS, HS, SIP scores, and Illness Intrusiveness.

The referents that trauma survivors used in providing their LS and HS ratings revealed a great degree of overlap. LS ratings were primarily attributed to attitudes, limitations in interests and activities, physical and emotional symptoms, personal/social life, and physical fitness (listed in order of frequency of responses). HS ratings were attributed differentially depending on whether the ratings were good or poor. Favorable HS ratings were primarily ascribed to feeling well physically, and emotionally, positive attitudes, lack of limitations in interests and activities, and social support. Less favorable

HS ratings were ascribed to physical symptoms/disease, limitations in interests and activities, being physically unfit, employment related concerns, and fear of re-injury. Despite the great deal of overlap evident, reports of poor health were more often attributed to physical symptoms/illness, whereas better health was less often attributed to the presence or absence of disease or illness and more focused on psychosocial factors. The results of the SIP assessment indicated that although sickness has a greater impact on psychosocial areas of functioning than physical areas of functioning, physical function remains a concern for trauma survivors at 1 to 2 years post-injury.

Recreation and pastimes, social interaction, work, finances, and health were life domains that were identified as the primary concerns to trauma survivors, and were repeatedly identified in the various sections of the study instrument; discussion of the referents used in rating LS and HS, in the SIP, and in the Illness Intrusiveness Scale (both Part I: Illness Intrusiveness and Part II: perceived control).

The major hypotheses generated from this study to test in future research include:

- 1) Males and females differ with respect to mechanism of injury among trauma survivors.
- 2) More women than men do not return to work post injury.
- 3) Socioeconomic status, as measured by education level, is lower among trauma survivors than the general population.
- 4) Male trauma survivors provide higher LS and HS ratings than female trauma survivors.
- 5) LS ratings among trauma survivors are at least as high as those provided by the general population.
- 6) LS ratings among severe head and spinal cord injured trauma survivors are lower than those provided by other trauma survivors and the general population.
- 7) Self rated HS is slightly lower among trauma survivors than the general population.
- 8) Self-rated HS is lower among those surviving severe head and spinal cord injuries than other trauma survivors and the general population.
- 9) The categories of referents used to rate HS and LS are similar.

- 10) Trauma survivors are concerned with their physical functioning at one to two years post injury.
- 11) LS and self reported HS are more strongly associated with psychosocial variables than physical variables among trauma survivors at one to two years post injury.
- 12) Subjective factors are the primary determinants of LS and self rated HS in trauma survivors.
- 13) Illness Intrusiveness compromises QOL in trauma survivors.
- 14) Illness Intrusiveness is greater among individuals surviving severe head and spinal cord injuries than other trauma survivors.
- 15) Sickness Impact is greater among trauma survivors at one to two years post injury than the general population.
- 16) Sickness Impact is greater among those with severe head and spinal cord injuries than other trauma survivors.
- 17) LS, HS, Sickness Impact, Illness Intrusiveness, and perceived control are all significantly associated among trauma survivors.

Study Limitations

The response rate was only 63.6%, therefore, the study conclusions may not be entirely representative of the population of trauma survivors. Sample size was not considered a limiting factor at study onset because the purpose of this descriptive study was to identify potential associations to be tested in future research, however, the sample size may have been too small to identify potential associations between the outcome variables and some of the demographic variables. This study did not include trauma survivors residing in rural areas, individuals who had suffered severe head injuries, and those who had spinal cord injuries, therefore the conclusions used to generate hypotheses from this study may not apply in those populations. The generalizability of this study is limited due to the size of sample and study criteria employed.

LS ratings differed between respondents and non respondents, with non respondents providing lower ratings of LS. Therefore, the high ratings of LS reported among this sample of trauma survivors may be higher than the population of trauma survivors from which the sample was drawn. As well, only 35.7% of non-respondents agreed to answer LS and HS questions over the telephone, making comparison of respondents and non respondents with respect to outcome weak.

One final potential study weakness is that the Illness Intrusiveness Scale may be biased toward finding some degree of intrusiveness among those who respond to the scale, because there is no category for responding that one feels no intrusiveness at all from illness. Categories on the scale are from 1 (not very much) to 7 (very much).

Recommendations for Future Research

This study provides the reader with a descriptive study of the LS, HS, and Illness Intrusiveness of trauma survivors. It should act as a basis for future research efforts. As discussed in the Methods section of this thesis, potential associations were identified in conducting this research which serve the purpose of generating testable hypotheses for future research. The associations identified need to be tested in well planned studies with a large sample size. It would be interesting to include rural residing trauma survivors, which would significantly increase the sample size and allow for determination of the effect of residence on outcome variables. It is important to offer a home interview as an alternate to elderly and women in order to maximize the response rate. Many individuals indicated that they would not have been able to participate if required to travel for the interview. Lengthening the time period over which telephone contacts are made could decrease the number of eligible individuals who are excluded due to inability to contact.

An ongoing study with active surveillance is recommended due to the lack of information regarding long-term outcomes of trauma survivors. Keeping track of large numbers of individuals over many years is a major challenge in highly mobile populations, and a major portion of study staff must be devoted to follow-up (Kelsey, Thompson, &

Evans, 1986). The current Trauma Registry needs to improve tracking capacity for follow-up studies. This can be accomplished in several ways. The name, address, and telephone number of someone who does not live with, but is likely to know the whereabouts of the individual who was hospitalized, and is considered to be more permanently located, should be added to the Registry. Women should have their married name, maiden name, and parent's surnames included in the Registry as well. Alberta Health Care Numbers, effective 1995, are unique identifiers carried for a lifetime and should be included in the Registry for record linkage. Record or computer linkage can be accomplished through motor vehicles branches, provincial registries, birth records, credit bureaus, or the postal service (Kelsey et al., 1986). Telephone directories should be consulted for tracing individuals as well. At hospital discharge, all patients should be approached for permission to be contacted for future study and explained the importance of obtaining an understanding of the long term outcomes of people subject to trauma. Individuals should be contacted regularly (e.g., every 3 to 6 months) to verify information.

No problems were encountered with the use of the SIP or the Illness Intrusiveness Scale in this sample of trauma survivors, however, individuals with severe head injuries were excluded. There is an urgent need for the development and validity determination of tools for use in the cognitively impaired as a result of head injury.

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APPENDIX A
Letter From Trauma Directors

To:

We are writing to let you know about a study that is being done in the next couple of months, looking at the long-term outcomes of trauma survivors. The outcomes of particular interest include overall health status and life satisfaction, as perceived by the trauma victims, and the degree to which the long-term consequences of the traumatic event impede the pursuit of valued interests and activities. All individuals who were injured between April 1, 1993 and March 31, 1994, who live in Calgary, and did not sustain severe head or spinal cord injuries are being contacted to participate.

Lana McFadden, a graduate student in the department of Community Health Sciences of the University of Calgary, will be conducting personal interviews during the months of May and June. These interviews will take approximately 40 minutes to an hour to complete. Your involvement and input into the exploration of long-term outcomes of this population would be very valuable and much appreciated.

Lana will begin telephoning all eligible individuals to discuss the possibility of participation after May 1, 1995. If you do not wish to receive a telephone call please call the following number by May 1, 1995: 220-4281. If no one is available to take your call please leave a message on the answering machine. Otherwise, you will receive a call in the following weeks to discuss whether or not you would be interested in participating in this study. At the time of Lana's telephone call you may consent or refuse to participate. Any questions you might have regarding your participation may be addressed at that time.

If you have any questions concerning your rights as a possible participant in this research please contact the Office of Medical Bioethics, Faculty of Medicine, the University of Calgary, at 220-7990.

Thank-you for taking time to read this letter.

Sincerely,

Trauma Coordinator
Calgary General/Foothills Hospital

Director of Trauma Services
Calgary General/Foothills Hospital

APPENDIX B

Telephone Script for Contacting Potential Participants

Hello. My name is Lana McFadden and I am calling on behalf of the trauma team of the (Calgary General of Foothills Hospital). The reason I am calling is that we are conducting a study in order to explore the long-term outcomes of trauma survivors. We are looking specifically at the outcomes of health, as perceived by the individual, their overall satisfaction with life, and the degree to which the long-term consequences of the injury disrupt valued interests and activities. The reason we are doing this study is that very little is known regarding the long-term outcomes of people who have been subject to traumatic injury.

I am calling to see whether you would be interested in being involved in this project. Your involvement would require participation in a personal interview that would take from 40 minutes to one hour to complete. Do you have any questions about what I have explained to you? Are you interested in participating? Yes _____ No _____

(If yes) Would you mind answering two quick questions now, prior to the interview?
Yes _____ No _____

(If no) Would you be willing to respond to two brief questions so we can determine whether the people we interview are representative of the urban trauma population?
Yes _____ No _____

If yes:

1) How much satisfaction and enjoyment of life do you generally feel? (circle number)

- 1 - A lot of satisfaction and enjoyment
- 2 - Fairly much satisfaction and enjoyment
- 3 - Very little satisfaction and enjoyment
- 4 - Absolutely no satisfaction and enjoyment

2) How would you describe your health right now? (circle appropriate number)

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

APPENDIX C

Consent Form

Research Project: Self-Reported Health, Life Satisfaction, and Illness Intrusiveness in Trauma Survivors

Investigators: Dr. M. L. Russell, Dr. J. Kortbeek, Dr. R. Lafreniere, and L. McFadden

This consent form, a copy of which you will retain, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned or not mentioned in this form, feel free to ask. Please read this carefully.

The purpose of this research project is to gain knowledge regarding the long-term outcomes of trauma survivors. The outcomes of particular interest in this study will be health status, as perceived by you, your degree of satisfaction with life, and the degree to which the traumatic event has impeded the pursuit of valued interests and activities.

The information obtained through this study will be a valuable contribution to knowledge regarding long-term outcomes of trauma survivors. This knowledge may form the basis for future research and efforts toward improving the health status and life satisfaction of trauma survivors. In this way, the research would provide a benefit to society.

Involvement in this study will require participation in an interview that will take approximately one hour to complete. The interview will require you to respond to a number of questions regarding your perceptions of your health status, your satisfaction with life, and the degree to which your health status intrudes on your pursuit of valued interests and activities.

Your signature on this form gives consent to the investigators to access information in the Trauma Registry of the hospital in Calgary where you were treated (information such as injury type and severity, length of stay in hospital, etc.). It is important to access this information in order to explore other factors which may contribute to your present health status and satisfaction with life. Your signature also gives permission for the interview to be tape-recorded. Your responses to open-ended questions will be tape-recorded in order to ensure that the interviewer does not miss documenting important information.

Access to the information collected will be initially limited to the investigators listed on this consent form. However, all information identifying you will subsequently be removed and numerical coding will be used to identify the information in order to provide anonymity. Other investigators may then have access to the data, but will not have any information to link that data to you. All of the data will be kept in a locked filing cabinet within a secure office for a period of five years, upon which time it will be destroyed. The tapes used to record the open-ended responses will be destroyed after transcription, with codes for identification, to protect anonymity. The results will be reported in a pooled fashion, to prevent individual identification. A summary of these results will be mailed out to all participants upon the completion of the research project.

Your signature on this form indicates that you have understood, to your satisfaction, the information regarding your participation in the research project, and that you agree to participate. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. If you have further questions concerning matters related to this research, please contact:

Lana McFadden	or	Dr. M. L. Russell
220-4281		220-4286

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

(Name of participant)

(Signature of participant)

(Name of witness)

(Signature of witness)

(Name of Principle Investigator)

(Signature of Principle Investigator)

(Date)

A copy of this consent form will be given to you for your records and future reference. Will you allow the research team to contact you in the future about participating in specific research projects? Saying yes does not commit you to taking part in those studies, but allows us to contact you. At the time of contact you may consent or refuse. Should you consent, your name and hospital identification number will be recorded on a master list and kept in a locked filing cabinet within a secure office for a period of five years, upon which time it will be destroyed.

Yes _____ No _____

Signature _____

APPENDIX D

Study ID _____

Hospital ID _____

Health and Life Satisfaction Questionnaire

Interview Date: _____ (mm/dd/yy)

Interview Start Time: _____

Demographic Information:What **age** are you? _____ (in whole numbers)

Sex: Male _____ Female _____ (check appropriate response)

Which of the following responses would best describe your **marital status**? (circle appropriate number)

1. Never married
2. Currently married or common-law
3. Divorced or separated
4. Widowed

How many **children** do you have? (circle appropriate number)

1. None
2. One to two
3. Three or more

Are you a **primary caregiver** of your children?

Yes _____ No _____

Were you **working outside your home** prior to your injury? (check response)

Yes _____ No _____

If yes, how many **hours per week** were you working then? (circle corresponding number)

1. < 10 hours/week
2. 10 - 19 hours/week
3. 20 - 29 hours/week
4. 30 - 39 hours/week
5. at least 40 hours/week

What was your **occupation** prior to your injury? _____

Study ID Number: _____

Are you **working now**? (check appropriate response)

Yes _____ No _____

If yes, how many **hours per week** are you working now? (circle corresponding number)

1. < 10 hours/week
2. 10 - 19 hours/week
3. 20 - 29 hours/week
4. 30 - 39 hours/week
5. at least 40 hours/week

What is your **occupation now**? _____

If participant's occupation is different post-injury:

Is the **reason you've changed occupations** related to your injury? (check response)

Yes _____ No _____

What is the **highest education level** that you have achieved? (circle number)

1. Grade 9 or less
2. Some high school, no diploma
3. High school diploma
4. Some post secondary education, no diploma or degree
5. College diploma
6. University degree

Did you have any **illnesses prior to your injury**? (check response)

Yes _____ No _____

If yes, what were the illnesses? _____

Are you involved in **litigation** related to your injury? (check response)

Yes _____ No _____

Study ID Number: _____

Global Life Satisfaction:

- 1) How much satisfaction and enjoyment of life do you generally feel? (circle number)
- 1 - A lot of satisfaction and enjoyment
 - 2 - Fairly much satisfaction and enjoyment
 - 3 - Very little satisfaction and enjoyment
 - 4 - Absolutely no satisfaction and enjoyment

Open-ended Description:

Why do you rate your satisfaction with life that way?

Descriptive Notes	Reflective Notes

Global Health Status:

- 2) How would you describe your health right now? (circle number)
- 1 - Excellent
 - 2 - Very good
 - 3 - Good
 - 4 - Fair
 - 5 - Poor

Open-ended Description:

3) Why do you rate your health that way?

Descriptive Notes	Reflective Notes

Study ID Number: _____

Illness Intrusiveness Scale: (circle appropriate numbers)

Please rate the following items on the degree to which the consequences of your accident disrupts interests and activities that you value. Rate each item on a scale of 1 to 7, 1 meaning that effects of the trauma do not disrupt valued interests and activities very much, and 7 meaning that effects of the trauma disrupt interests and activities very much.

Life Domains	Intrusiveness	Control
1. Work	1 2 3 4 5 6 7	1 2 3 4 5 6 7
2. Active recreation	1 2 3 4 5 6 7	1 2 3 4 5 6 7
3. Passive recreation	1 2 3 4 5 6 7	1 2 3 4 5 6 7
4. Financial situation	1 2 3 4 5 6 7	1 2 3 4 5 6 7
5. Relationship with spouse	1 2 3 4 5 6 7	1 2 3 4 5 6 7
6. Sex life	1 2 3 4 5 6 7	1 2 3 4 5 6 7
7. Family relations	1 2 3 4 5 6 7	1 2 3 4 5 6 7
8. Other social relations	1 2 3 4 5 6 7	1 2 3 4 5 6 7
9. Self-expression/Self-improvement	1 2 3 4 5 6 7	1 2 3 4 5 6 7
10. Religious expression	1 2 3 4 5 6 7	1 2 3 4 5 6 7
11. Community and civic involvement	1 2 3 4 5 6 7	1 2 3 4 5 6 7
12. Health	1 2 3 4 5 6 7	1 2 3 4 5 6 7
13. Diet	1 2 3 4 5 6 7	1 2 3 4 5 6 7

Please rate the same items on the degree to which you feel that you have control over each of these areas of life. Rate each item on a scale of 1 to 7 again, 1 meaning you feel you have no control, and 7 meaning that you have a great degree of control.

Study ID Number: _____

Sickness Impact Profile: © Johns Hopkins University 1977 (used with permission)

Instructions To The Respondent:

Before beginning this part of the questionnaire, I am going to read you the instructions.

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or long-standing. I am interested in learning about any changes that describe you today and are related to your state of health.

I will be reading statements that people have previously said describes them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As I read the questionnaire, think of yourself today. I will pause briefly after each statement. When you hear one that does describe you and is related to your health please tell me and I will check it.

Let me give you an example. I might read the statement "I am not driving my car." If this statement is related to your health and describes you today, you should tell me. Also, if you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, this statement is not related to your health and you should not respond to it. If you simply are driving less, or are driving shorter distances and feel that the statement only partially describes you, please do not respond to it.

I am now going to begin this section. Please tell me if you want me to slow down, repeat a statement, or stop so that you can think about one. Also let me know any time if you would like to review the instructions. Remember we are interested in the recent or long-standing changes in your activities that are related to your health.

Please respond to ONLY those statements that you are sure describe you TODAY and are related to your state of health.

Study ID Number: _____

Items the participant responds to should be marked with a check and others left blank.

Sleep and Rest: (SR-0499)

1. I spend much of the day lying down in order to rest _____ (070-083)
2. I sit during much of the day _____ (062-049)
3. I am sleeping or dozing most of the time - day and night _____ (063-104)
4. I lie down more often during the day in order to rest _____ (066-0585)
5. I sit around half-asleep _____ (065-084)
6. I sleep less at night, for example, wake up too early, don't
fall asleep for a long time, awaken frequently _____ (069-061)
7. I sleep or nap more during the day _____ (071-060)

Emotional Behavior: (EB-0705)

1. I say how bad or useless I am, for example, that I am a burden
on others _____ (274-087)
2. I laugh or cry suddenly _____ (272-068)
3. I often moan and groan in pain or discomfort _____ (269-069)
4. I have attempted suicide _____ (281-132)
5. I act nervous or restless _____ (262-062)
6. I keep rubbing or holding areas of my body that hurt or are
uncomfortable _____ (262-062)
7. I act irritable and impatient with myself, for example, talk
badly about myself, swear at myself, blame myself for
things that happen _____ (273-078)
8. I talk about the future in a hopeless way _____ (283-089)
9. I get sudden frights _____ (278-074)

Body Care and Movement: (BCM-2003)

1. I make difficult moves with help, for example, getting into or
out of cars, bathtubs _____ (168-084)
2. I do not move into or out of bed or chair by myself but am
moved by a person or mechanical aid _____ (170-121)
3. I stand only for short periods of time _____ (155-072)
4. I do not maintain balance _____ (146-098)
5. I move my hands or fingers with some limitation or difficulty _____ (152-064)

Study ID Number: _____

- | | |
|---|-----------------|
| 6. I stand up only with someone's help | _____ (165-100) |
| 7. I kneel, stoop, or bend down only by holding onto something | _____ (171-064) |
| 8. I am in a restricted position all the time | _____ (158-125) |
| 9. I am very clumsy in body movements | _____ (148-058) |
| 10. I get into and out of bed or chairs by grasping something for support or using a cane or walker | _____ (169-082) |
| 11. I stay lying down most of the time | _____ (162-113) |
| 12. I change position frequently | _____ (147-030) |
| 13. I hold onto something to move myself around in bed | _____ (143-068) |
| 14. I do not bathe myself completely, for example, require assistance when bathing | _____ (310-089) |
| 15. I do not bathe myself at all, but am bathed by someone else | _____ (312-115) |
| 16. I use bedpan with assistance | _____ (292-114) |
| 17. I have trouble getting shoes, socks, or stockings on | _____ (305-057) |
| 18. I do not have control of my bladder | _____ (290-124) |
| 19. I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces | _____ (298-074) |
| 20. I spend most of the time partly undressed or in pajamas | _____ (302-074) |
| 21. I do not have control of my bowels | _____ (295-128) |
| 22. I dress myself, but do so very slowly | _____ (300-043) |
| 23. I get dressed only with someone's help | _____ (297-088) |

Home Management: (HM-0668)

This group of statements has to do with any work you usually do in caring for your home or yard.

- | | |
|--|-----------------|
| 1. I do work around the house only for short periods of time or rest often | _____ (117-054) |
| 2. I am doing less of the regular daily work around the house than I would usually do | _____ (119-044) |
| 3. I am not doing any of the regular daily work around the house that I would usually do | _____ (120-086) |
| 4. I am not doing any of the maintenance or repair work that I would usually do in my home or yard | _____ (001-062) |
| 5. I am not doing any of the shopping that I would usually do | _____ (106-071) |
| 6. I am not doing any of the house cleaning I would usually do | _____ (116-077) |

Study ID Number: _____

7. I have difficulty doing handwork, for example, turning faucets,
using kitchen gadgets, sewing, carpentry _____ (107-069)
8. I am not doing any of the clothes washing that I would usually
do _____ (111-077)
9. I am not doing heavy work around the house _____ (115-044)
10. I have given up taking care of personal or household business
affairs, (i.e., paying bills, banking, working on budget) _____ (105-084)

Mobility: (M-0719)

1. I am getting around only within one building _____ (134-086)
2. I stay within one room _____ (128-106)
3. I am staying in bed more _____ (130-181)
4. I am staying in bed most of the time _____ (131-109)
5. I am not now using public transportation _____ (140-041)
6. I stay home most of the time _____ (133-066)
7. I am only going to places with restrooms nearby _____ (125-056)
8. I am not going into town _____ (124-048)
9. I stay away from home only for brief periods of time _____ (139-054)
10. I do not get around in the dark or in unlit places without
someone's help _____ (121-072)

Social Interaction: (SI-1450)

1. I am going out less to visit people _____ (028-044)
2. I am not going out to visit people at all _____ (029-101)
3. I show less interest in other people's problems, for example,
don't listen when they tell me about their problems, don't
offer to help _____ (003-067)
4. I often act irritable toward those around me, for example,
snap at people, give sharp answers, criticize easily _____ (015-084)
5. I show less affection _____ (007-052)
6. I am doing fewer social activities with groups of people _____ (012-036)
7. I am cutting down the lengths of visits with friends _____ (027-043)
8. I am avoiding social visits from others _____ (034-080)
9. My sexual activity is decreased _____ (039-051)

Study ID Number: _____

10. I often express concern over what might be happening to my health _____ (018-052)
11. I talk less with those around me _____ (002-056)
12. I make many demands, for example, insist that people do things for me, tell them how to do things _____ (038-088)
13. I stay alone much of the time _____ (023-086)
14. I act disagreeable to family members, for example, I act spiteful, or am stubborn _____ (249-088)
15. I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them _____ (240-119)
16. I isolate myself as much as I can from the rest of the family _____ (237-102)
17. I am paying less attention to the children _____ (238-064)
18. I refuse contact with family members, for example, turn away from them _____ (256-115)
19. I am not doing the things I usually do to take care of my children or family _____ (242-079)
20. I am not joking with family members as I usually do _____ (255-043)

Ambulation: (A-0842)

1. I walk shorter distances or stop to rest often _____ (050-048)
2. I do not walk up or down hills _____ (046-056)
3. I use stairs only with mechanical support, for example, handrail, cane, crutches _____ (042-067)
4. I walk up/down stairs only with assistance from someone else _____ (044-076)
5. I get around in a wheelchair _____ (057-096)
6. I do not walk at all _____ (052-105)
7. I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg _____ (049-055)
8. I walk only with help from someone _____ (053-088)
9. I go up and down stairs more slowly, for example, one step at a time, stop often _____ (040-054)
10. I do not use stairs at all _____ (041-083)
11. I get around only by using a walker, crutches, cane, walls, or furniture _____ (047-079)
12. I walk more slowly _____ (051-035)

Study ID Number: _____

Alertness Behavior: (AB-0777)

1. I am confused and start several actions at a time _____ (223-090)
2. I have more minor accidents, for example, drop things, trip
and fall, bump into things _____ (234-075)
3. I react slowly to things that are said or done _____ (228-059)
4. I do not finish things I start _____ (227-067)
5. I have difficulty reasoning and solving problems, for example,
making plans, making decisions, learning new things _____ (224-084)
6. I sometimes behave as if I were confused or disoriented in
place or time, for example, where I am, who is around,
directions, what day it is _____ (231-113)
7. I forget a lot, for example, things that happened recently,
where I put things, appointments _____ (222-078)
8. I do not keep my attention on any activity for long _____ (220-067)
9. I make more mistakes than usual _____ (225-064)
10. I have difficulty doing activities involving concentration
and thinking _____ (217-080)

Communication: (C-0725)

1. I am having trouble writing or typing _____ (191-070)
2. I communicate mostly by gestures, for example, moving head,
pointing, sign language _____ (177-102)
3. My speech is understood only by a few people who know
me well _____ (179-093)
4. I often lose control of my voice when I talk, for example, my
voice gets louder or softer, trembles, changes unexpectedly _____ (197-083)
5. I don't write except to sign my name _____ (188-083)
6. I carry on a conversation only when very close to the other
person or looking at him _____ (178-067)
7. I have difficulty speaking, for example, get stuck, stutter,
stammer, slur my words _____ (176-076)
8. I am understood with difficulty _____ (200-087)
9. I do not speak clearly when I am under stress _____ (201-064)

Study ID Number: _____

The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis.

Do you usually do work other than managing your home

Yes No

If you answered no:

Are you retired?

Yes No

If you are retired, was your retirement related to your health?

Yes No

If you are not retired, but are not working, is this related to your health?

Yes No

You may skip the next set of questions (1-9)

Work: (W-0515)

If you answered yes:

- | | |
|--|-----------------|
| 1. I am not working at all | _____ (100-361) |
| 2. I am doing part of my job at home | _____ (094-037) |
| 3. I am not accomplishing as much as usual at work | _____ (096-055) |
| 4. I often act irritable toward my associates, for example, snap at them, give sharp answers, criticize easily | _____ (088-080) |
| 5. I am working shorter hours | _____ (095-043) |
| 6. I am doing only light work | _____ (086-050) |
| 7. I work only for short periods of time or take frequent rests | _____ (090-061) |
| 8. I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers | _____ (092-034) |
| 9. I do not do my job as carefully and accurately as usual | _____ (097-062) |

Study ID Number: _____

This group of statements has to do with activities you usually do in your free time. These activities are things that you might do for relaxation, to pass the time, or for entertainment.

Recreation and Pastimes: (RP-0422)

1. I do my hobbies and recreation for shorter periods of time _____ (215-039)
2. I am going out for entertainment less often _____ (214-036)
3. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading _____ (207-059)
4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading _____ (208-084)
5. I am doing more inactive pastimes in place of my other usual activities _____ (211-051)
6. I am doing fewer community activities _____ (216-033)
7. I am cutting down on some of my usual physical recreation or activities _____ (210-043)
8. I am not doing any of my usual physical recreation or activities _____ (209-077)

Eating: (E-0705)

1. I am eating much less than usual _____ (085-037)
2. I feed myself but only by using specially prepared food or utensils _____ (073-077)
3. I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar _____ (081-043)
4. I eat no food at all but am taking fluids _____ (077-104)
5. I just pick or nibble at my food _____ (083-059)
6. I am drinking less fluids _____ (080-036)
7. I feed myself with help from someone else _____ (074-099)
8. I do not feed myself at all, but must be fed _____ (075-117)
9. I am eating no food at all, nutrition is taken through tubes or intravenous fluids _____ (076-133)

Study ID Number: _____

We have now completed this interview. Are there any **additional comments or concerns** that you have, related to your health, that were not adequately addressed by the interview questions?

Descriptive Notes	Reflective Notes

Interview Stop Time: _____

Total Interview Time (minutes): _____