

FUNCTIONAL, PSYCHOLOGICAL AND COMMUNITY INTEGRATION CHANGES OVER
TIME IN PERSONS WITH MAJOR BURN INJURY

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DEDICATION

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FUNCTIONAL, PSYCHOLOGICAL AND COMMUNITY INTEGRATION CHANGES OVER
TIME IN PERSONS WITH MAJOR BURN INJURY

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The purpose of the present study was to measure prospectively the functional, psychological and community integration status of individuals with major burn injury in order to determine the extent of changes over time and how functional and community integration status relates to emotional distress. This study was part of the North Texas Burn Model System Grant funded by the National Institute on Disability and Rehabilitation Research. Subjects in this study included adults over 14 years of age who met the American Burn Association's criteria for a major burn injury. The Total Body Surface Area burn across the measurement periods in these subjects ranged from 22.4 to 25.2 percent. Data was collected from 356 participants at discharge, 199 participants at 2 months, 255 participants at 6 months, 193 participants at 12 months, 114 participants at 24 months and 41 participants at 36 months. The instruments used in this study were the Brief Symptom

Inventory (BSI), the Burn Specific Health Scale (BSHS), The Community Integration Questionnaire (CIQ), the Pain Analog Scale (PAS) and the Functional Assessment Screening Questionnaire (FASQ). It was hypothesized that 1) both areas of functioning and community integration would improve as emotional distress abated and that 2) the functional improvement and community integration as well as the lessening of emotional distress would continue over time. A repeated measures ANOVA was used to measure changes over time and a Bonferroni Multiple Comparison Test was used to compare results at different time intervals. FASQ and CIQ total scores for individuals exhibiting high versus low measures of emotional distress (with median split of BSI global scores) were compared at each measurement period using the Student's T-test. A statistically significant interaction was found between the variables as predicted; however, the participants in this study appeared to reach a plateau at 24 months after which little change in outcomes was noted.

TABLE OF CONTENTS

CHAPTER ONE	Introduction.....	1
CHAPTER TWO	Literature Review.....	4
	Prevalence of Burn Injury.....	4
	Advances in Medical Treatment of Burn Injury.....	5
	Psychological Factors in Burn Injury.....	8
	Summary.....	43
CHAPTER THREE	Methodology.....	46
CHAPTER FOUR	Results.....	53
CHAPTER FIVE	Discussion.....	66
APPENDIX A	Description of Burn Injury Severity.....	81
APPENDIX B	Brief Symptom Inventory (BSI).....	82
APPENDIX C	Pain Analog Scale (PAS).....	84
APPENDIX D	Functional Assessment Screening Questionnaire (FASQ).....	85
APPENDIX E	Burn Specific Health Scale (BSHS).....	86
APPENDIX F	Community Integration Questionnaire (CIQ).....	90
BIBLIOGRAPHY	92

LIST OF FIGURES

FIGURE 4-1	Distribution of Study Sample by Etiology of Burn Injury.....	55
FIGURE 4-2	Scores on the Brief Symptom Inventory (BSI) Indicating Changes Over Time in Somatization, Anxiety, Global Severity Index and Positive Symptom Severity Index.....	56
FIGURE 4-3	Change Over Time Intervals in Least, Worst and Current Pain Scores on the Pain Analog Scale (PAS).....	57
FIGURE 4-4	Improvement in Functional Ability over Time as Shown by Scores on the Functional Assessment Screening Questionnaire (FASQ)...	58
FIGURE 4-5	Change Improvement in Overall Quality of Life Over Time as Shown by Scores on the Burn Specific Health Scale (BSHS).....	59
FIGURE 4-6	Total Scores on the Community Integration Questionnaire (CIQ)...	60
FIGURE 4-7	Productivity Scores on the Community Integration Questionnaire (CIQ).....	61
FIGURE 4-8	Improvement in Functional Ability (FASQ score) among Burn Patients - High and Low Emotional Distress (BSI-GSI score).....	63
FIGURE 4-9	Improvement in Functional Ability (FASQ score) among Burn Patients with High and Low Psychological Distress (BSI-PSDI score).....	63
FIGURE 4-10	Improvement in Community Integration (CIQ score) among Burn Patients - High and Low Emotional Distress (BSI-GSI score).....	64

FIGURE 4-11 Improvement in Community Integration (CIQ) among Burn Patients with High and Low Psychological Distress (BSI-PSDI score)..... 65

LIST OF TABLES

TABLE 4-1	Demographic Characteristics of Study Participants.....	54
TABLE 4-2	Total Body Surface Area (TBSA) of Burn of Study Participants Across Study Time Intervals.....	54
TABLE 4-3	Median Split of High-Distress and Low-Distress Groups on BSI- GSI and BSI-PDSI at each Follow Up Interval.....	62

CHAPTER ONE

Introduction

Since ancient times, burn injuries have been a primary origin of individual trauma. The treatment of burns through the generations has encompassed a vast array of remedies ranging from primitive herbal medicines to complex advanced medical and surgical regimens (Patterson, Everett, Burns, & Marvin, 1993). Almost no other recovering population finds themselves confronted with the magnitude and severity of challenges as those faced by individuals who survive severe burns. Survivors not only must experience and withstand the initial pain and trauma of the burn incident, but then must undergo lengthy treatment and rehabilitation that focuses on physical and cosmetic impairment as well as emotional difficulties (Patterson et al., 1993). Fauerbach, Lawrence, Haythornthwaite, McGuire, & Munster (1996) commented that burns involve traumatization, bereavement, pain and disfigurement. Unlike those who sustain mild to moderate burns, those survivors of severe burns may find themselves faced with a disfigured body that does not function as it did preinjury. There is frequently a real sense of having become a “different person” than the individual who existed preburn. Many times the future occupational role of the person is in question at best and in jeopardy of being totally eradicated at worst. In addition to these traumas, many individuals experience disturbing and confusing emotional reactions such as depression and anxiety ranging in intensity from mild to debilitating. Confronted with the fact that nearly all the objective or external factors that contribute to the image of self have been irreversibly altered, the individual is then called upon to muster a myriad of coping and adaptive resources. While in the midst of attempting to cope with such challenges, the person must also begin to redefine him or herself, now taking into consideration appearance changes, physical impairments, alterations in social roles and occupational changes.

Integrating the psychological and social functional aspects of burn recovery into the overall medical and rehabilitation treatment has come to fruition in the last three to four decades. Because of the low survivability of major burn injuries before this time, there were few studies that addressed morbidity issues. Due to advances in burn care, mortality rates declined, and comprehensive rehabilitation treatment issues became a priority.

The Coconut Grove fire in Boston in 1942 was the catalyst that originally stimulated interest in burn outcomes; prior to this tragedy, the interest in such outcomes was virtually nil and almost no psychological research had been undertaken. Literature in the early 1970s noted that “surprisingly, few people have studied the burn patient from the psychiatric point of view” (Andreasen, Norris & Hartford, 1971). The limited research that was done stated findings of minor psychological complications with the most common diagnoses being those of “general nervousness” or “anxiety neurosis” in about half the “victims” at one year follow up (Adler, 1943; Cobb & Lindemann, 1943).

New ideas concerning the measurement of health status were first addressed by Sigerist (1941) who originally theorized that in order to be healthy, a person had to be well-balanced physically, mentally, and socially. He concluded that the mere absence of disease was not a sufficient measure of health. He, in essence, proposed what is currently the widely accepted biopsychosocial model of functioning. This idea was further substantiated by Iwao Moriyama (1968) whose classic article identified the inadequacies of using death rates as the exclusive measurement of health status. By the 1980s measurements of health status had progressed, and not only were dysfunction and disability being considered, but also measures of physical, psychological and social factors were being developed (Bergner, 1984). Another influence on outcomes that began to be studied was premorbid conditions.

With the establishment of specialized burn facilities in the late 1970s and early 1980s, survival rates increased again, this time dramatically, and the medical community began seriously focusing on the physical, psychological and social outcomes (Chang & Herzog, 1975; Patterson et al., 1993). Consequently, the effects of the presence of premorbid psychological symptoms, acute postburn psychological reactions, and the long-term adjustment of survivors began to be studied. Current research is focusing on a plethora of issues ranging from the effects of premorbid functioning on postburn adaptation to the impact of burn injury on vocational and community reintegration.

CHAPTER TWO

Literature Review

PREVALENCE OF BURN INJURY

Each year approximately 1.5 to 2.0 million Americans sustain burn injuries, 70,000 to 100,000 of which will be serious enough to require hospitalization. Of those individuals, 35,000 to 50,000 develop temporary to permanent disability (Helm, Fisher & Cromes, 1998). An individual's chances of sustaining a burn requiring hospitalization in one's lifetime are approximately 1 in 70 (MacArthur & Moore, 1975). Burns result in approximately 5,500 deaths per year and are the fourth leading cause of injury in the United States, exceeded only by motor vehicle collisions, falls and drowning (Wiechman et al., 2001). The most recent studies find that the combined cost of the care of burn patients exceeds 1 billion dollars per year (Bongard et al., 1985; Demling, 1986 as cited in Rockwell, Dimsdale, Carroll & Hansbrough, 1988). Bull (1971) reported that in the 1960s there was a 50% mortality rate in individuals who sustained a total body surface area (TBSA) burn of 30% or more. In their 15-year retrospective study, Prasad, Bowden & Thomson (1991) reported an increase in survival rates from 78% in 1970 to 94% by 1985; these findings were especially noted in individuals who sustained larger TBSA burns. The incidence of death directly related to burn injuries has continued to drop substantially since that time to a reported 5,500 burn-related deaths in 1991 (Brigham & McLoughlin, 1996). Current statistics reflect a greater than 50% survival rate for individuals incurring 80% TBSA burns (Wiechman et al., 2001), with some individuals surviving even 90% TBSA burns (Heimbach, Engrav, & Marvin, 1981). It is theorized that this drastic increase in survivability may be attributed not only to improvements in burn care, but also to the discovery and implementation of successful strategies of prevention of burns (Brigham & McLoughlin, 1996). Consequently, as greater

numbers of individuals began to survive their burn injuries, an increase in morbidity emerged. There were now pertinent factors relating to survivability that had not previously been of much concern, and rehabilitation became a priority (Prasad et al., 1991).

ADVANCES IN MEDICAL TREATMENT OF BURN INJURY

As survival rates continued to increase, trends in the quality of burn care began to be more closely scrutinized. As data began to show that overall survival rates were increasing and hospitalization times were decreasing at all levels of burn severity, possible factors responsible for these changes began to be studied.

In one study, case reports from burn care facilities were collected through the National Burn Information Exchange (NBIE), a facility created in 1964 for the express purpose of collecting, storing and evaluating data in order to track the quality of the burn care at specialized burn care facilities. This study reviewed reports collected from 1965 through 1979 involving 37,442 burn survivors. Findings reflected consistently improved survival rates over time for every age group. Trends in the quality of burn care were also examined with survival and length of hospitalization being two of the important outcome variables.

The most significant change was noted in individuals between 0-59 years of age, and timely wound closure for full thickness burns was one of the factors associated with the evident changes in survival (Feller, Tholen & Cornell, 1980). According to Bull (1971), another factor contributing to increased survivability was the introduction of the practice of guarding against infection with 0.5% silver nitrate solution. It was also noted that, regardless of burn size, there was at least a 25% decrease in length of hospital stays from 1965 to 1971 (Feller et al., 1980). In an editorial commenting on the Feller et al., 1980 study, Pruitt

(U.S. Army, 1980) suggested “another mechanism being at least in part responsible for the improved survival recorded is the referral of patients to specialized treatment facilities so that the conversion of second-degree burns to full-thickness injuries might be prevented.”

Consequently, in response to the need for a facility that could offer the complex care needed by individuals sustaining serious burns, specialized burn care facilities were developed. According to Heimbach et al. (1981),

These facilities are usually self-contained units devoted specifically to the care of burned patients. While the proper physical environment is important, the amalgamation of a multidisciplinary team, all members of which understand the problems unique to burned patients, is the crucial factor (pg. 275).

Specific guidelines have been set forth by the American Burn Association and the American College of Surgeons' Committee on Trauma regarding the burn injury characteristics that require treatment at a specialized burn care facility. Specialized treatment is recommended for individuals who have sustained 30% or greater TBSA burns; persons over 65 years of age or children younger than three; those who sustained electrical burns or deep burns of the hands, face, feet or perineum; and individuals who experienced smoke inhalation or other injuries in addition to their burn.

Several pathophysiological factors are unique to the burn population and require immediate attention to maintain survivability. Loss of fluids, inhalation injury, infection and high metabolic rate pose real threats to the physical recovery of a burn victim.

Fluid resuscitation, which involves immediate replacement of the large amounts of fluid lost through capillary damage and evaporation, requires immediate and specialized attention. According to a widely used formula known as the Parkland formula, a lactate solution is given in amounts that would seem incredulous to physicians who were not experienced with burns (Heimbach et al., 1981). This electrolyte solution is dispensed according to the TBSA burn injury and the individual's weight and must be administered

within 48 hours of sustaining the burn (Cromes & Helm, 1999), with usually half the amount being given within the first eight hours and the other half given in two equal amounts within the next 2 eight-hour time frames. With this rapid fluid replacement, the incidence of renal failure, which is most often fatal, can be greatly decreased (Heimbach et al., 1981).

Carbon monoxide poisoning due to smoke inhalation is the leading cause of death in fires. Statistics show that mortality rates in individuals with TBSA burns of less than 70% are most often associated with smoke inhalation (Heimbach et al., 1981).

Infection has been shown to be the most common cause of mortality in burn patients, inasmuch as “virtually every aspect of ...immunity is disrupted following a severe burn” (Heimbach et al., 1981, pg. 277). Improvement in this area over the last few decades has greatly decreased the death rate. Prior to World War II, 30% of individuals who sustained burns died from ensuing infection within one week. With the introduction of penicillin, this number initially decreased only to have the patients expire in the second and third week due to antibiotic-resistant infections. With the introduction of topical antibiotic agents to inhibit bacterial growth, infection could be controlled in relatively moderate size burns, effectively lowering the death rate somewhat (Bull, 1971).

In larger burns, however, antibiotic resistant pathogens continued to break through, causing widespread wound sepsis. By the 1960s and early 1970s, such infections were the most common cause of death (Heimbach et al., 1981). One 6-year retrospective study reported that sepsis had occurred within about nine days in 14% of the individuals treated (Ng, Anastakis, Douglas & Peters, 1991). As burn treatment improved, early wound closure – consisting of immediate and aggressive wound excision and grafting – was discovered to be one of the main factors in the area of sepsis prevention.

According to Heimbach, Engrav & Marvin (1981), "A burn provides the greatest sustained stress and highest metabolic response of any known insult...and metabolic rates can at least double by the time the burn reaches 40% TBSA" (pg. 277). Since it is virtually impossible for an individual to consume sufficient quantities of food to adequately provide for their increased metabolic requirements, it is imperative they be monitored by a specially trained dietician who can supervise the individual's nutritional intake, which is then supplemented by continuous enteral tube feeding. This provision of adequate nutritional supplementation has directly contributed to decreased mortality and has also allowed many burn patients to maintain up to 95% of their preburn weight (Heimbach, Engrav & Marvin, 1981).

PSYCHOLOGICAL FACTORS IN BURN INJURY

Importance of Psychosocial Factors in Outcome Measurement

Questad et al. (1988, pg. 87) stated, "Until fairly recently, the 'outcome' of a major burn was virtually synonymous with patient survival." This statement is certainly true of the period preceding the 1960s. Moriyama (1968) addressed the use of death rates as the exclusive measurement of health status. Taking into consideration the increased life expectancy in the United States, which rose from 47.3 years in 1900 to an average life expectancy at birth of 70.2 years in 1964, Moriyama (1968) contended that "mortality data...are no longer adequate as measures of 'health' of the population" (pg. 576). In this statement Moriyama (1968) was echoing concepts expressed Dr. Henry Sigerist (1941), who defined a healthy individual as

...a man who is well-balanced bodily and mentally, and well adjusted to his physical and social environment. He is in full control of his physical and mental facilities, can adapt to environmental changes so long as they do not exceed normal limits; and contributes to the welfare of society according to his ability. Health is, therefore, not simply the absence of disease: it is something positive, a joyful attitude toward life, and a cheerful acceptance of the responsibilities that life puts on the individual. (pg. 100)

What Siegerist (1941) was in essence proposing is the biopsychosocial model which addresses not only the physical state of well being, but also takes into consideration the individual's psychological and social functioning.

Of major concern was the fact that the primary measures of health status were based on the negative facets of health, and that between the states of well being and death, there were really no uniformly agreed upon stages. Lerner and Anderson (1963) stated that in addressing the measurement problem, "health levels are now most adequately measured when mortality rates are supplemented by morbidity rates and even by other measures of social well-being" (as cited in Moriyama, 1968, pg. 580-581). With the improvements in the quality and sophistication of burn care (Currerie, Braun & Shires, 1980) and as survival rates continued improving over time (Feller et al., 1980), the medical community itself became aware that mortality statistics were no longer a sufficient measure of burn outcomes.

During the 1970s there evolved both an increased emphasis on and awareness of the interaction between the psychological, social and physical aspects of a disability on overall outcomes in populations other than those involving individuals with burns. Accordingly, as burn survivors were beginning to regain much of their preburn functioning, there became an increased realization of the need to consider these same components when seeking to measure functional outcomes within that population. Blades, Jones & Munster (1979), in discussing the need for such a diagnostic instrument, noted the following:

...mortality statistics are the only currently available measurement by which to gauge the effect of burn therapy. The extent to which survivors are able to return to preinjury levels of social and psychological adjustment, work capacity and functional ability is unknown...In populations other than the burn injured, there is increasing emphasis on behavioral, social and clinical outcome studies (p. 556-557).

Concomitant to the fact that early outcomes were based exclusively on survivability, such outcomes were also often based strictly on pathophysiological sequelae rather than any form of psychological model (Browne et al., 1985). Within the medical model, "physical symptoms [were] assumed to be primary determinants of psychological outcomes" (Patterson, Ptacek, Cromes, Fauerbach & Engrav, 2000) leading to some widely held misassumptions. One such belief was that the more functionally disabling a person's injuries, the poorer his emotional recovery (Elliott & Frank, 1996). Another mistaken theory was that there was a correlation between the size of the burn and the individual's adjustment capabilities. Both predictions have since been repeatedly repudiated (Blades et al., 1979; Patterson et al., 2000; Madianos, Papaghelis, Loannovich & Dafni, 2001). In fact, Blades et al. (1979) stated that "premorbid factors are just as important in determining the outcome of the injury as is the degree of the burn" (pg. 558).

Most of the studies regarding the psychological impact of injuries on individuals who sustained burns fall into three categories: (1) the study of the prevalence of premorbid psychological problems in individuals who experienced burns; (2) the examination of acute psychological reactions postburn; and (3) the investigation of long term adjustment of burn survivors (Patterson et al., 1993). Regarding the importance of addressing psychological concerns, Blumenfield & Schoeps (1992) noted, "obstacles in the way of psychological recovery match the challenges of physical reconstruction and rehabilitation" (pg. 599).

Prevalence of Premorbid Psychological Problems in Burn-Injury Patients

It has long been observed that, within the burn population, those sustaining injuries of sufficient severity to require hospitalization seem more likely to exhibit some form of premorbid psychological dysfunction. Consequent studies have confirmed the presence of several forms of psychopathology common in individuals who sustained burns (Patterson et al., 1993). There is a greater prevalence of preexisting psychiatric problems within the burn-surviving adult population than is found in the general populace (Brezel, Hassenbrock & Stein, 1988; Fauerbach et al., 1997), and psychiatric illness represents a primary determinant in the predisposition to burn injury (Rockwell et al., 1988; Fauerbach et al., 1997). Wiechman et al. (2001) stated, "We know that psychiatric difficulties put persons at increased risk for a burn injury and these patients are over-represented in the burn population" (pg. 423).

Estimates regarding the presence of preinjury psychopathology in individuals sustaining burns vary widely, but even in early studies it was suggested that with systematic psychiatric evaluation, high rates of psychopathology were present in this population (Andreasen & Norris, 1972). Kolman (1983) historically reviewed eight early studies in which the presence of premorbid psychopathology was examined, and found estimates of its presence that ranged from 2.8% to 28%. Estimates of premorbid psychiatric problems or history by other researchers have ranged from 10.4 % (Ward, Moss, Darko, & Berry, 1987) to 28% (Brezel et al., 1988) to 45% (Noyes, Frye & Slymen, 1979). Strikingly, Davidson & Brown (1985) in their 5-year retrospective study of self-inflicted burns, reported finding psychiatric dysfunction in 75% of their population. Other factors implicated in the predisposition of individuals to burn injuries were neurological disease, mood disorders and

antisocial or borderline personality disorder (MacArthur & Moore, 1975; Rockwell et al., 1988; Fauerbach et al., 1997). The most prevalent premorbid psychiatric diagnoses among individuals with burn injury are depression, personality disorder and alcohol or substance abuse (Brezel, Hassenbrock & Stein, 1988; Rockwell et al., 1988; Noyes et al., 1979; MacArthur & Moore, 1975).

More current studies have only reinforced these findings. Fauerbach et al. (1997) reported,

...particular aspects of affective, alcohol and substance use categories of disorder may increase the risk of burn injury. For example, affective, alcohol-related and substance use disorders are all related to diminished cognitive processing (e.g., difficulty thinking or concentrating), while alcohol and substance use disorders are also related to difficulties with impulse control. Perhaps these groups of individuals are less inhibited, less able to plan ahead, or have greater difficulty in monitoring their activities than...adults without such history of psychiatric disorder... (pg. 381-382).

In addition to preburn psychopathology, the profile of individuals who “have a predisposition to being burned” (Ward et al., 1987, pg. 297) often includes a high-stress, high-risk lifestyle. In a study by Noyes et al. (1979), 40% of the study population was unemployed and half was from the lowest socioeconomic group. Within this group, a significant increase in stressful life events in the year preceding the burn was reported. Unemployed individuals incur an unusually high rate of burn injuries, often sustained in a more risk-enhanced fashion than is observed in employed individuals. According to Rockwell et al. (1988), “While these actions are not intentional, the patients’ carelessness and disregard places them at jeopardy” (pg. 86). A later study indicated that a more complex psychiatric history effectively increases the likelihood that an individual will not be employed at the time the burn is sustained (Fauerbach et al., 1997).

Impact of Preburn Psychological Factors on Postburn Treatment and Recovery

Psychiatric complications often negatively impact functioning during hospitalization. Patients may resort to premorbid dysfunctional adaptation modes such as regression, depression or poorly controlled hostility (Andreasen & Norris, 1972). Individuals with a preburn affective or substance use diagnosis exhibited a significantly increased likelihood of developing, within the same category, either a similar postburn disorder (Fauerbach et al., 1997), more serious psychiatric complications, or a comorbid psychiatric disorder following a burn injury (Roca, Spence & Munster, 1992; Steiner & Clark, 1977). Fauerbach et al. (1997) concluded, "...the high prevalence of lifetime and 12-month postinjury disorder in the burn-surviving adult population was confirmed" (pg. 381). Individuals with a psychiatric history tend to require longer hospital stays, especially for those with a diagnosis of schizophrenia, a personality disorder or dementia (Berry, Wachtel & Frank, 1982).

Grobmyer, Maniscalco, Purdue & Hunt (1996) further elaborated these findings in their study of the correlation between alcohol and/or drug intoxication at the time of injury and subsequent complications. According to their study, individuals who were intoxicated at the time of injury exhibited an increased likelihood of physical complications such as loss of skin grafts and the development of cellulitis, pneumonia or hypotension. These individuals also had more admissions into intensive care units, required more ventilator days, needed more transfusions and operations and concomitantly spent more total days in the hospital.

Research has indicated that the presence of a premorbid psychiatric disorder can also negatively impact the adjustment capabilities of individuals sustaining burns. These findings were reported by Fauerbach et al. (1996) in their study of the overall prevalence of lifetime psychiatric disorders as well as their examination of the impact of preburn

psychiatric morbidity on the postburn functional adjustment of burn survivors. The most prevalent premorbid diagnoses in this study population were alcohol abuse (41%) and mood disorder (30.5%). Outcome measures were taken at discharge, and again at both 4 months and 12 months post discharge. Compared to individuals who displayed no prior psychiatric difficulties, each of the groups exhibiting premorbid psychiatric problems showed more extensive adjustment problems at discharge. However, in this study, at 4 months postdischarge, the functional levels of the diagnostic group was equivalent with the “no diagnosis” subjects; further, these improvements were maintained and reflected again in the 12 month data. These findings suggest that the presence of a preburn psychiatric diagnosis tends to acutely exacerbate both the initial impact and initial impairment of the burn trauma in this population, and may predict initial adjustment difficulties.

While the summary of the literature involving these studies substantiates the theory that those individuals exhibiting premorbid psychopathological disorders are more likely to sustain burns and be increasingly prone to both longer and more complicated periods of recovery, it would be remiss to omit the possible limitation of these conclusions. Of obvious concern in studying research in retrospect is the fact that the records were not initiated with any type of psychiatric diagnosis as their focus. Therefore, because of the absence of standardized measures, eliciting valid comparisons is difficult. A coexisting limitation involves a lack of comparative data between the burn population and the overall general populace. Without appropriate control-group comparison, the actual frequency of psychopathology in those with burns cannot be appropriately determined. However, in spite of these limitations, the frequency and consistency of psychosocial maladaptation among the burn population simply cannot be ignored (Patterson et al., 1993).

Acute Psychological Reactions After Burn Injury

During the critical care phase of recovery, especially in severely burned individuals, the outcome is often fraught with uncertainty, and the focus, quite literally, is on survival (Avni, 1980). Because of this uncertainty regarding survivability and the trauma of repeated emergency procedures, this can be a time of severe distress, both physically and psychologically for the patient. Individuals often perceive the ICU environment as a strange and frightening place where they often experience alternating extremes of overstimulation and understimulation (Steiner & Clark, 1977).

Once the patient is medically stable, the acute care phase begins. While the environment is often perceived as more familiar and less intrusive, the individual must now begin rehabilitation while undergoing medical treatments that often involve skin grafting and painful dressing changes (Patterson et al., 1993). Concurrently, the individual must also begin to cope with an increased awareness of both the physiological and psychological long-term impact of the burn trauma (Patterson, 1987).

Two of the most common symptoms noted in burn survivors, especially in the earlier stages of recovery, are delirium and psychosis. These reactions are usually transitory in nature and may range from mild disorientation and confusion to illusions or hallucinations and often are thought to be caused by sensory overload and deprivation, sleep deprivation or an adaptive psychological defense in reaction to the shock of a threatening event (Hamburg, Hamburg & deGoza, 1953; Patterson, 1987). These symptoms are also prevalent in older patients, individuals with larger TBSA burns or those who were heavily medicated with narcotic analgesics (Patterson et al., 1993).

According to Perry & Blank (1984), any distinct changes in mental status are usually attributable to electrolyte imbalance, metabolic complications or some pathophysiologic cause such as alcohol withdrawal or infection. Within this study, those individuals who experienced delirium were more likely to be male and to exhibit a substance abuse history. There was also a correlation between larger TBSA burns and delirium as well as a greater probability of a fatal outcome. Currently, studies suggest that between one-third and one-fifth of burn patients may experience some mild transient delirium. However, true delirium is often indicative of a more severe physiological complication that requires prompt diagnosis and treatment (Patterson et al., 1993).

Other symptoms that often occur in the acute care phase of recovery are anxiety, especially acute stress disorder (ASD) and/or post-traumatic stress disorder (PTSD), depression, and behavioral problems (Kolman, 1983; Patterson, 1987). However, studies have indicated that poor hospital adjustment was associated with premorbid psychological dysfunction and with TBSA burned (Andreasen & Norris, 1972; Steiner & Clark, 1977). Interestingly, while rates of depression and anxiety in burn survivors parallel those observed in comparable hospitalized samples (Choiniere, Melzack, Rondeau, Giraard, & Paquin, 1989), both delirium and PTSD are manifested more frequently in burn survivors than in other patients (Patterson et al., 1993).

Impact of Psychological Factors on Post-Acute and Long-Term Adjustment

Studies of the long-term effects of burn injuries are countless and involve research examining periods ranging from acute reaction to outcomes involving more than a decade post injury (Patterson et al., 1993). However, even early literature noted that the first year

post trauma is the time during which morbid dysfunction tends to be most apparent (Andreasen & Norris 1972; Blades et al., 1979; Chang & Herzog, 1975; Sheffield et al., 1988).

Although during the first year postburn many individuals may confront myriad stress factors, many are, as suggested by both historical and current literature, considered to be transient in nature. Vivid memories, the loss of loved ones, strains in family and marital relations, work issues and disruptions of daily life are just some of the issues that must be addressed (Patterson et al., 1993).

While some aspects of postburn trauma appeared to subside with time, other features, such as those involving self-esteem and emotional adjustment, tended to become evident later – sometimes years after sustaining the burn (Bowden, Feller, Tholen, Davidson & James, 1980). Depression, especially in those whose burns involved the hands and/or face, was found to be quite common, with an average duration of approximately one year postburn (Chang & Herzog, 1975). Various studies noted, however, that within one to two years posttrauma, the majority of patients reported a decrease in their depressive symptomatology and were able to resume their preinjury levels of functioning with regard to work, recreation and interpersonal and family relationships (Chang & Herzog, 1975; Andereasen et al., 1971; Andreasen & Norris, 1972). However, Chang & Herzog (1975) also noted that often the major emotional adjustment for the patients did not occur until after being released from the hospital when “[without] the constant reinforcement of the doctors, nurses and therapists, [the patient] was [then] confronted with the realities of [the] disability” (pg. 37).

Postburn Physical and Psychosocial Adjustment Factors

Patterson et al. (2000), in their study examining whether psychosocial or medical/physical factors best predict postburn adjustment, found that it is not one specific factor, but the cumulative interaction of the physical and psychological as well as the social factors that are involved. These findings correlated with those of Browne et al. (1985), in which not only psychosocial but also socioeconomic variables were identified as being prevalent in individuals exhibiting adjustment problems postburn. Therefore, as “physical and psychological problems do not exist in clinical isolation but interact to affect treatment outcomes” (Wiechman et al., 2001, pg. 424) there developed an increased focus on long-term rehabilitation with approaches designed to improve both physical and psychological adjustment. This led burn centers to recognize the value of implementing the biopsychosocial model in the overall treatment of individuals with burns since “identify[ing] and respond[ing] to the patient’s psychological distress [proved] integral to the burn patient’s recovery and rehabilitation” (Wiechman et al., 2001, pg. 424). One such example of the interaction between physical trauma and long-term psychological adjustment was reported by Altier, Malenfant, Forget, & Choiniere, (2002), who stated that individuals experiencing sensations in their healed wounds reported psychological symptoms at a greater rate than those individuals who did not experience such tactility. Recent research has revealed several other factors that are now thought to affect the development of psychological complications and impact the quality of life experienced by the patient, posttrauma (Patterson et al., 2000). Some of these involve the structure of a person’s personality as a determinant of an increased likelihood of experiencing post-traumatic stress disorder (Fauerbach, Lawrence, Schmidt, Jr., Munster, & Costa, Jr., 2000), and a premorbid history

of mood disorders as a predictor of a decreased quality of life in health-related areas (Fauerbach, Lawrence, Munster, Palombo & Reichter, 1999; Fauerbach et al., 2000). Research suggests that preexisting personality traits may determine how some individuals experience positive and negative events (Headey & Wearing, 1989; Ormel & Schaufeli, 1991). This is an important factor in that personality cannot be separated from functioning and can influence treatment issues. Mangus, Diener, Fujita & Pavot (1993) reported that extraversion was strongly related to positive events while neuroticism showed a strong correlation to negative events. These researchers theorized that neurotic individuals possibly react to a wider variety of events in a negative way, thereby creating negative emotions that lead to the creation of more negative events. Consequently, a negative outlook could serve to hinder positive treatment outcomes.

Burn Specific Psychological Treatment Needs

According to Patterson et al. (1993), the effects of burn injuries are multifaceted, often involving extreme anxiety, pain and disfigurement. Burn injuries differ from most other types of trauma and illness in that they are not restricted to any particular demographic group, but are experienced by the general populace. The majority of cases reflect that initially, burns tend to have a severe impact on individuals, but in many patients the long-term effects can be minimal. Often immediate and burn-specific psychological treatment can help facilitate the recovery process. Of concern is the fact that often individuals do not exhibit symptoms clinically significant enough to actually warrant a diagnosable disorder, but they nonetheless experience distress sufficient to cause psychological difficulty. In concurrence, Madianos et al. (2001) reported:

The psychological assessment of the patients with burn injuries during the third week of hospitalization and then at 12 months follow-up, revealed that psychopathologic symptoms of distress were very common. The prevalence of psychological impairment based on the accumulation of self-reported symptoms of *anxiety*, *hopelessness* and *helplessness* on the Langner scale, at the baseline and the 12 months follow-up reached 45.5 and 40.0% respectively. These symptoms, although they do not represent clear cut nosological entities, but rather a subjective experience of hopelessness-helplessness resulting in demoralization, are considered as an expression of psychopathology (pg. 34, italics in original).

Wiechman et al. (2001) also proffers that when referring to depression, even though individuals may not clinically meet the criteria for a specific diagnosis, their symptoms of distress can nonetheless interfere with both their quality of life and their recovery and should therefore be treated accordingly. However, unlike early literature which determined postburn adjustment outcomes solely on the presence of a diagnosable psychiatric disorder (Adler, 1943; Andreasen et al., 1971; Andreasen & Norris, 1972), current literature recognizes the fact that “the presence of a psychiatric diagnosis is an insufficient method of quantifying the psychological reactions to a major burn injury, particularly if a person was well-adjusted before the injury” (Patterson, Everett, Burns & Marvin, 1992; Patterson et al., 1993, as cited in Patterson et al., 2000, pg. 490).

According to Faber, Klasen, Sauer, & Vuister (1987), however, the cycle of recovery is dynamic. Initially 40% of their population reported psychological symptomatology, but only a little more than 20% required psychological assistance within 18 months of discharge. In contrast, Holbrook, Anderson, Sieber, Browner, & Hoyt (1998, 1999) and Holbrook, Hoyt, & Anderson (2001a, 2001b) found clinically significant psychological complications in about 25% of the burn population they examined at 5 years postburn.

Anxiety

Many times a burn injury can be life threatening in nature, producing a “brush with death” that consequently disrupts normal psychological defenses, while acutely delineating the vulnerability and mortality of the individual. Since it is uncommon for individuals to even consider the possibility that they could die at any given moment, to be suddenly confronted with the fact often produces anxiety so marked and pervasive that it can persist long after the physiological wounds have healed (Blumenfield & Schoeps, 1992). Patterson et al. (2000) noted that while a certain number of patients may actually meet the clinical criteria necessary for a formal psychological diagnosis as described in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR, 2000), most will not. However, a large majority of survivors have been observed to experience at least some of the negative symptoms related to associated anxiety disorders such as adjustment disorder, acute stress disorder (ASD) or post-traumatic stress disorder (PTSD).

Post-Traumatic Stress Disorder

Within the realm of anxiety, the first and most serious anxiety disorder, according to the DSM-IV-TR, is posttraumatic stress disorder (PTSD). In PTSD, anxiety develops in response to a person experiencing a traumatic event involving the threat of serious injury or death or an actual death. In order to be diagnosed with PTSD, the individual must exhibit certain symptoms, including persistent re-experiencing of the trauma, a persistent desire to avoid stimuli associated with the trauma, a numbing of responsiveness in general, and increased arousal. In order to meet the criteria for a formal diagnosis of PTSD, the person

must experience these disturbances for more than a month, and the symptoms must cause either clinically significant distress or impairment in an important area of functioning.

Although not all burn survivors experience PTSD, a notable number do. According to Ehde, Patterson, Wiechman, & Wilson (2000), at both one month and one year post injury, approximately 50% of their sample reported experiencing recurrent intrusive distressing memories of the trauma, and 40% reported sleep disturbance and avoidance of associated thoughts and feelings. According to this study, only one of five burn survivors was free of symptoms at one year. Because a strong correlation was found between the endorsement of PTSD symptomatology at one month and one year, it was theorized that early experience of post-traumatic distress may be associated with both the development and maintenance of PTSD.

Madianos et al. (2001) reported an increase over time in post-traumatic symptomatology. While slightly less than 18% of the burn patients in their study were diagnosed with PTSD during the third week post-injury, 20% exhibited symptoms sufficient for an actual diagnosis by the one year follow-up. Additionally, at both baseline and follow-up, an average of 44% of the study population met at least three quarters of the criteria necessary for a PTSD diagnosis; and at the one year follow-up, nearly half the population met the criterion for a specific psychiatric disorder, the majority being mood disorders.

There are other noteworthy factors regarding burn survivors diagnosed with PTSD. When compared to burn patients without this syndrome, individuals experiencing PTSD had larger TBSA burns, reported more severe pain and were more likely to experience delirium. They were less likely to have been responsible for their burn but they demonstrated more guilt concerning the precipitating trauma (Perry, Cella, Falkenberg, Heidrich & Goodwin, 1987). Overall, however, long-term outcome findings vary tremendously. Patterson et al.

(1993) reported that although PTSD appears to be quite common in burn injuries, it is also most often a transient psychological complication. This statement is in direct contradiction to findings by Madianos et al. (2001), of an increase over time of distressful symptomatology.

Acute Stress Disorder

Another relevant anxiety disorder, acute stress disorder (ASD), essentially has many of the same diagnostic requirements as PTSD, except the disturbance must occur within 2 days of the traumatic event and not persist beyond 4 weeks. Awareness of ASD is particularly important because there is a predictive relationship between early experiences of ASD and both acute and chronic PTSD (Ehde, et al., 2000).

In a study of acute stress symptoms after burn injury, 51% of individuals in the study reported sleep disturbance and 35% reported having nightmares & flashbacks (Lipowski, 1983). Wallace & Pegg (1999) reported that 31% of adults who sustained burns experienced symptoms sufficiently disturbing to warrant psychological intervention. This is similar to findings reported by Andreasen & Norris (1972), in which 30% of their population expressed psychological distress secondary to the burn injury, with 20% of the experienced symptoms being considered mild and the other 10% being classified moderate to severe.

Adjustment Disorder

Although not considered specifically an anxiety disorder, a diagnosis of adjustment disorder is also a distinct possibility in burn patients. According to the DSM-IV-R, a diagnosis of adjustment disorder, as with PTSD and ASD, requires the presence of a psychosocial stressor. However, while both PTSD and ASD require that the stressor be extreme and a specific criterion of symptoms be met in order for a diagnosis to be made, in adjustment

disorder the symptomatology can have been “triggered by a stressor of any severity and may involve a wide range of possible symptoms” (DSM-IV, 1994, pg. 626). One of the criteria necessary for a diagnosis of adjustment disorder is that the symptoms of distress persist less than 6 months once the stressor has been terminated.

Is Psychiatric Intervention Necessary?

There are conflicting opinions regarding the necessity of psychiatric intervention for individuals exhibiting anxiety symptoms. Browne et al. (1985) reported nonspecific psychological symptoms in 40% of individuals postburn, and stated that “90% of adults adjusted as a function of time without a systematic intervention” (pg. 34). Andreasen & Norris (1972) stated that although acutely most individuals display significant traumatic symptomatology including insomnia, emotional lability, disproportionate sensitivity, anxiety, nightmares and ruminative thinking, in most individuals (70%) such symptoms “gradually diminish without treatment, becoming much less troubling after several months and absent after about a year” (pg. 357). They also observed that within two years of the initial burn trauma, most of the individuals examined in the study had returned to pre-burn levels of functioning in the areas of interpersonal and family relationships, work and leisure activities. In contrast, Wiechman et al. (2001) advocated early identification and treatment of emotional complications, stating that such distress “will not likely subside over time if left untreated” (pg. 423).

Depression

Depression has been identified as one of the most common and potentially damaging psychological outcomes that affect recovery within the burn population (Wiechman et al., 2001). Severe depression appears to be a non-disease-specific complication within hospitalized medical patients in general, being observed in approximately 20% of that population (Rodin & Voshart, 1986). However, burn patients are particularly vulnerable to depression because of the negative impact of burn injury on body image and self-esteem in terms of scarring, disfigurement, loss of functional capabilities and altered physical attractiveness. "...A significant number of apparently well-adjusted people become clinically depressed after their injuries" (Ward et al., 1987, pg. 297).

Self-concept has been shown to be negatively impacted by burns, especially in women. Wiechman et al. (2001) reported that at each measurement interval (1 month, 1 year and 2 years), women consistently reported higher depression scores than men, especially women who had sustained burn injury to the head or neck. Accordingly, such self-devaluation in body image is associated with both low self-esteem and depression (Orr, Reznikoff & Smith, 1989). Both Battle (1978) and Bowden et al. (1980) report finding a relationship between low self-esteem and depression. Fisher & Cleveland (1965) concluded that depressed people are more likely to have negative perceptions of their bodies, feel more worthless and have lower self-esteem than those who are not. According to Andreasen et al. (1971), "This problem is probably best conceived of as an abnormally prolonged grief reaction, during which the patient is actually mourning for a portion of his or her identity which has been lost through injury and deformity" (pg. 791).

Prevalence of Depression in Burn-Injured Patients

Reports of rates of depression within the burn population have varied, with in-hospital rates of severe depression ranging anywhere from 15% to 38% (Andreasen & Norris, 1972; Klein & Charlton, 1980). Post discharge depression rates vary from 25% to 65% up to a year afterward (Patterson et al., 1993). In their study of long-term rates and severity of depression after burn injuries, Wiechman et al. (2001) reported that, "At 1 month, 54% of patients showed symptoms of moderate to severe depression and at 2 years, 43% of the patients responding still reported moderate to severe depression" (pg.417). According to Madianos et al. (2001), the prevalence of depression among the burn population may be more than five times as high as among the general population.

Some features of postburn trauma, such as emotional adjustment, can emerge months or even years after the burn injury was sustained (Bowden et al., 1980). Ward et al. (1987) reported depression rates of 12.9% less than 2 years after burn injury, 18.5% at 2 to 4 years, and 34.9% at more than 4 years. Such findings suggest that the occurrence of clinically significant depression may tend to increase rather than decrease as a function of time. These findings delineate the possible need for psychological intervention beyond the point of hospital discharge (Ward et al., 1987).

Impact of Depression on Recovery

The numerous complications faced by burn injury survivors are often exacerbated by the presence of any type of mood disorder. Depression is particularly troublesome because of its innately multifaceted nature which often has a dramatic effect on both physical and psychological functioning. Each specific aspect of functioning, whether physiological, cognitive, emotional or social interfaces with other functional characteristics, thereby

influencing the individual's overall recovery (Wiechman et al., 2001). In several studies initiated by Herbert & Cohen (1993), they consistently found a correlation between depression and an alteration in the immune system, which consequently increases the likelihood of infection in burn patients. Depression can also have a negative effect on other components of the rehabilitation process, such as social interactions, consistency regarding treatment and medication adherence, and return-to-work (Carney, Freeland, Eisen, Rich, & Jaffe, 1995).

Predictors of Depression

There are conflicting data regarding other factors that various studies (e.g., Browne et al., 1985; Ward et al., 1987) have identified as being predictors of a burn survivor's tendency to develop depressive symptoms. Ward et al. (1987) found there was no correlation between a person's percent burn, age, sex, marital status, educational or economic level and the development of postburn depression. On the other hand, Madianos et al. (2001) cited several studies identifying socioeconomic level, vocational status (i.e. whether the person is employed, unemployed or has lost a job), age at the time of burn and educational history as being related to the development of postburn depression. Browne et al. (1985) stated, "Those disadvantaged in the first instance by poverty, unemployment or physical disability were further disadvantaged in their adjustment to the burn event" (pg. 28).

As previously stated, another dynamic that appears to impact depression is a premorbid history of psychopathology (Fauerbach et al., 1999; Fauerbach et al., 2000; Madianos et al., 2001). In fact, in a long-term study in which individuals were evaluated from years one through eight following a burn injury, Ward et al. (1987) reported that "...it is the person, rather than the injury, that best predicts postburn depression. The factor most

strongly linked with depression was a past history of emotional disturbance” (pg. 294). Some researchers agree that individuals who experience postburn depression probably had a premorbid history of depression (Rockwell et al., 1988). This view is substantiated by early studies, one of which reported that 38% of individuals exhibited pre-injury depression (Klien & Charlton, 1980). Such individuals with a pre-burn psychiatric history were found to be more likely to report low morale and also more likely to be depressed (Madianos et al., 2001). In their study, Ward et al. (1987) reported that of those individuals who reported having had premorbid psychiatric hospitalizations, 42% exhibited moderate to severe depressive symptoms at follow-up. This relationship between preburn problems and reaction to burn injury has also been corroborated by Patterson et al. (1993) and Wiechman et al. (2001).

Obviously many factors can contribute to the development of depression and as Wiechman et al. (2001) noted earlier, the different aspects of this multifaceted disorder interrelate, leading to increased distress in the individual. Another such factor involves level of pain, which has also been found to be predictive of depression in a trauma population. Studies involving patients who experienced a severe trauma injury reported that the presence of a permanent disability, the experiencing of a sense of loss of physical and environmental control or the presence of chronic pain were the greatest predictors for the development of depressive symptomatology (Turner & Noh, 1988; Welch, 1995).

Relationship Between Pain and Psychological Distress

Pain is a major factor for the burn patient, particularly during the acute phase of recovery, as it plays a significant role in an individual's psychological adjustment (Patterson et al., 1993). According to Blumenfield & Schoeps (1992),

...many recovered victims of burn injury, even after successful rehabilitation, will state that if they should ever have another burn injury, they would prefer to die than to go through the ordeal of being treated for a burn again. The most common reason given for this dramatic statement is 'pain' (pg.600).

Mersky (1986) described the pain of an individual who has sustained burns as "acute and severe at first following burn injury and later continuous with exacerbations gradually declining" (p.543).

Wounds that are deemed as not requiring a surgical procedure are subjected to wound debridement procedures which involve removal of necrotic tissue from the burn site, the application of antibacterial medications and the replacement of dressing and bandages. These procedures, referred to as dressing changes, are usually performed daily and require a time frame generally ranging from 30 minutes to an hour and a half (McNulty, 2002; Patterson et al., 1992). Wound debridement often involves excruciating pain that even the maximum dosages of opioids supplemented by anxiolytics or inhalants often proves inadequate to effectively control (Patterson et al., 1992). Perry, Heidrich & Ramos (1981) reported that 84% of their burn patient population described severe to excruciating pain during routine therapeutic procedures despite the customary administration of morphine. Consequently, it is the remedial procedures and not the burn itself that are considered to be the source of the most intense pain involved in burn treatment (Choiniere et al., 1989; Perry et al., 1981).

Individuals hospitalized with burns quite commonly reported their primary problem as being their attempt to cope with the acute pain (Davis & Sheely-Adolphson, 1997). Pain perception influences coping modalities, and similarly, a person's method of coping influences how pain is perceived. Thus, when pain is experienced as unbearable or uncontrollable, adaptive coping skills tend to deteriorate to more maladaptive responses such as catastrophizing or aggression (McNulty, 2002).

Additional psychological responses to pain are identified in various studies. Choiniere et al. (1989) reported that the more depressed individuals were, the more pain they were likely to report; and conversely, the more pain, especially resting pain, these individuals reported, the more likely they were to also become depressed. Romano & Turner (1985) found evidence supporting a correlation between chronic pain and depression, in that one third of individuals with chronic pain met the full diagnostic criteria for depression and another third expressed substantial depressive symptomatology. Likewise Perry, Cella, Falkenberg, Heidrich, & Goodwin (1987) found that patients demonstrating symptoms of PTSD during the acute hospitalization period reported more procedural and resting pain despite having been administered analgesic medication equivalent to that given to the general burn population under similar conditions.

Relationship Between Pain and Postburn Adaptation

It has also been theorized that not only can acute pain lead to chronic pain, but that the stress response to burn pain can maintain a shock cycle in traumatized burn patients that can not only delay wound healing, but also prolong the recovery process. Specifically this response can aggravate pathophysiology and potentially lead to hypoxia of the damaged

tissue, generate metabolic abnormalities and cause the release of toxins (Ptacek, Patterson, Montgomery & Heimbach, 1995). In an editorial entitled "Pain Can Kill", Liebeskind (1991) contended that immune system functioning can be both directly and indirectly suppressed by pain of sufficient magnitude.

Ptacek et al. (1995) reported study results suggesting that acute procedural pain during early hospitalization may directly impact postburn adaptation. Their findings indicated a positive correlation between the individual having experienced acute procedural pain within the first 5 days posttrauma and the person's psychosocial adjustment at one month after discharge. Also noted in the study was the fact that the pain factor proved to be a greater predictor of future adjustment than was either TBSA of the burn or the length of hospital stay.

Quality of Life and Self-Esteem After Burn Injury

One of the main factors in long-term adjustment is the maintenance of the trauma survivor's self-esteem (Patterson et al., 1993). Personal satisfaction in the pertinent areas of life such as health, leisure activities, interpersonal and community relationships, and the ability to sustain a sense of productivity all interconnect to comprise an individual's quality of life (Cobb, Maxwell, & Silverstein, 1990), and thereby directly impact self-esteem. Often, this quality of life is perceived by individuals as decreased after a burn injury. Although the self-esteem of many of the burn injured remains high, those who report a decrease in self-esteem usually also describe social withdrawal as a consequence (Patterson et al., 1993).

Blades et al. (1979) reported a quality-of-life rating in burn survivors of 89.9%, findings substantiated by Browne et al. (1985), who reported a maladjustment rate among

burn survivors of approximately 10%. Bowden et al. (1980), in their retrospective study of the self-esteem of severely burn patients, found adequate to high self-esteem in 85% of their population. Although no correlation was found between decreased self-esteem and the TBSA of the burn or the area of the body involved, self-esteem seemed to improve with time. It was found in this study that alcohol-dependent individuals as a group exhibited lower self-esteem than did other respondents. Also, individuals' involvement in social and recreational activities, their social support, their satisfaction with life and their employment were all found to be important factors in maintaining self-esteem.

Many times, the influence of a burn injury on self-esteem may be indirect "such as through the loss of employment or disfigurement" (Bowden et al., 1980, p. 452). Such a negative indirect influence can be further intensified by subsequent life changes and consequently may not become evident until many years post-injury. However, as studies have established a strong direct correlation between social support and self-esteem, it is theorized that problems arising several years after the burn injury may be, in part, related to the withdrawal of such support. Family and friends may gradually, over a period of time, subconsciously withdraw their support as they begin to perceive the burn survivor as recovered and no longer in need of emotional assistance. Therefore, although emotional support may be needed for a longer period of time than was once considered necessary, such assistance may tend to be more episodic in nature, depending more on concomitant life changes than on actual morbidity (Bowden et al., 1980).

Sexuality

Studies involving intimate relationships have yielded equivocal results. While Andreasen & Norris, (1972) reported no divorces and only one separation within their study,

Bowden et al. (1980) stated that approximately 25% of their study population reported experiencing marital problems as a result of sustained burn injuries. Chang & Herzog (1975) noted a divorce rate of 26% in their respondents, with the large majority of those who divorced having sustained burns to the face. However, overall there is scant evidence that individuals who were married postburn experience a greater degree of marital problems than the general populace. According to Andreasen & Norris (1972), many individuals, having nearly lost their lives,

almost invariably describe themselves as drawn closer to their spouses, as more trusting of them and aware of their loyalty and devotion, and as appreciative of being given a second chance to show their love for their partner [with] their awareness of their role within the family and the extent to which they are needed by their spouse or their children (being) intensified (pg. 359).

Decreased sexual satisfaction is prevalent in burn survivors, with women in particular appearing to exhibit more difficulty in this area than men, possibly because of the earlier discussed premium placed on physical attractiveness. Young women in particular reported less sexual enjoyment and fulfillment, with many stating that they no longer felt sexually desirable or physically attractive, despite reassurances from their partners to the contrary. Many reported that they preferred to undress in locations where they could not be observed by their mates. They also reported a tendency to dismiss assurance regarding their continued attractiveness and were inclined to be hypersensitive to remarks that could in any way be construed as negative or critical regarding their appearance (Andreasen & Norris, 1972; Tudahl, Blades & Munster, 1987).

According to Tudahl et al. (1987) in their study of the sexual satisfaction of burn patients, while men did show a decrease in sexual satisfaction level from 100% to 82.5%, women exhibited a more dramatic decrease, reporting only a 52% satisfaction level. Again, in women a strong negative correlation was found between sexual satisfaction in relation to

physical dysfunction and body image. However, no correlation was found between sexual satisfaction and either the size or location of the burn.

Functional Limitations After Burn Injury

When addressing functional limitations, it is important to recognize that both physical and emotional aspects of performance are involved (Klein, 1995). And while physical limitations are the areas of functioning most commonly addressed, possibly due to the fact that they are often easier to assess, the psychological aspect is of equal importance. Functional limitations involve two phases: the acute phase which refers to those limitations identified during actual hospitalization; and the post-acute phase, which refers to the problems experienced sometimes long after hospital discharge. Limitations occurring during the acute phase often tend to be self-limiting and are also less likely to produce permanent impairment than problems that occur later in the recovery process (Cromes & Helm, 1999).

Problems with functioning in the acute phase of a burn injury are often exacerbated by the medical procedures necessary for treatment (McNulty, 2002). Activities of self-care such as eating, grooming and toileting can be severely constricted by the presence of bulky dressings, splints used to immobilize a wound, both resting and procedural pain and/or edema (Cromes & Helm, 1999). Both mobility and communication may be restricted in those individuals who sustain an inhalation injury and consequently require the use of a ventilator (McNulty, 2002). Functional limitations are complicated by the psychological sequelae often experienced by burn survivors during this phase of recovery involving grief, fear of dying, nightmares and other sleep disturbances. Concomitant postburn anxiety or depression is often intensified by painful dressing changes, the fear of dependency and/or of the long term

consequences of the burn injury (Cromes & Helm, 1999). During this phase, there is also the challenge of adjusting to unfamiliar surroundings while contending with the loss of independence and the necessity of being cared for by strangers (Patterson et al., 1993). Realistically, during this phase of treatment, individuals may be required to relinquish control over the majority, if not all, areas of life for a time. To an individual who is of an independent personality type, such loss of control can be perceived as quite devastating (Holaday & McPhearson, 1997).

Individuals in this phase of recovery may regress to more child-like coping mechanisms in which they become emotionally labile, appearing aggressive and demanding one moment and then tearful, overly dependent and attention seeking in areas where they are actually functionally capable of attending to their own self-care (Browne et al., 1985; Davis & Sheely-Adolphson, 1997). Browne et al. (1985) noted that negative reactions to body image may emerge, along with other issues involving self-esteem, especially if the burn trauma involved the hands, face or genitalia.

It is during this time of recovery that outside influences can offer considerable support. According to Holaday & McPhearson (1997), in their study of the resiliency of burn survivors, interaction with peer role models served to not only decrease the sense of isolation often experienced by the burn injured, but also to assist in their adaptation to being hospitalized while offering a demonstration of healthy public social behaviors. Receiving emotional support from family members during this time can help facilitate patient adherence to both treatment programs and rehabilitation regimes (Browne et al., 1985). And although the actual acceptance and adjustment to the losses experienced by the burn survivor may take a long period of time, a general awareness of those losses during this early phase of recovery is important. Such cognizance can often help individuals achieve a

sense of their potential for resuming pre-burn levels of functioning in many areas of life (Patterson et al., 1993).

Hospital discharge defines the post-acute phase, but it does not terminate the healing process. Many individuals with burn injury must undergo numerous post-discharge treatments such as physical and occupational therapy, further skin grafting and/or reconstructive surgery (Cromes & Helm, 1999). During this time, several factors can contribute to limits in physical activity. Primary among these are loss of range of motion (contractures) due to scar tissue across joints. Contractures can limit ambulation if the lower extremities are involved and restrict lifting, carrying objects and manual dexterity if the upper extremities are involved (Helm, Fisher & Cromes, 1998; Klein, 1995). Grafted skin or burned skin that has healed may itch or even be painful. It is often inflexible, fragile, dry and intolerant to extremes in heat or cold; there may also be noticeable variations in pigmentation. Peripheral neuropathy may occur that causes the burn survivor to experience muscle weakness, impaired coordination and sensory loss. Visual impairment can result from contractures to the eyelids and/or corneal burns (Cromes & Helm, 1999), and individuals who sustain electrical contact on the head or shoulders may be predisposed to the formation of cataracts (Helm et al., 1998). In general, a major burn injury can result in impairment that affects functioning in a variety of areas.

Not to be minimized is the individual's loss of body integrity as well as his or her sense of safety in the world (Blumenfield & Schoeps, 1992). While burn trauma survivors may not consider themselves to be disabled, they may be perceived as so by others. Furthermore, not only friends and family, but also employers and co-workers may be hesitant to make social contact with the burned individuals because of the discomfort caused by their altered appearance (Bernstein, Breslau, & Graham, Eds., 1988).

Individuals may experience psychological distress similar to that felt during the acute phase of recovery. During this time, they may experience depression, fear, guilt and anxiety, any or all of which can negatively impact a person's functional ability (Ehde et al., 2000).

Social Support

Because research has consistently revealed that having a strong social support system is directly correlated to an increase in adjustment for burn survivors, social support systems are crucial to the recovery process (Browne et al., 1985; Holaday & McPhearson, 1997). According to Orr et al. (1989):

Perceived social support, especially from friends is the most important variable in determining adaptation to burn injury. Those patients with burns who believe they have been accepted by a group of friends report the most positive psychological responses after burn injury; they feel better about their bodies, have higher self-esteem and report less dysphoria (pg. 460).

These researchers also reported that greater perceived social support from friends and family directly correlated with a more positive body image. Such findings are not surprising given the significance that appraisal from others plays on one's own self-appraisal (Bowden et al., 1980). This is particularly true with the burn injured, as the sudden cosmetic disfigurement associated with burn injury can be overwhelming given the regard society places on stereotypical beauty. Sigall and Landy (1973), in their study on the effects of physical attractiveness on perception of others, found that observers tended to perceive attractive people as, "kinder, more genuine, sincere, warm, sexually responsive, poised, modest, sociable, sensitive, more exciting, more nurturing, and of better character" (p.289) when contrasted with people who were unattractive. The study also demonstrated that individuals who had attractive companions were considered to be more successful,

intellectual and exciting than those who had an unattractive partner (Sigall & Landy, 1973). Likewise, Dion, Berscheid and Walster (1972) noted that in a work evaluation, a positive correlation was found between a person's attractiveness and higher evaluation scores, scores which were also considered to reflect increased ability. Consequently, in the face of the pervasive stereotype that what is attractive is good, individuals who have sustained disfiguring burns can find the confrontation of the unpredictable nature of societal response quite daunting (McNulty, 2002).

Studies have shown that when an individual's appearance is outside the parameters of what is considered "normal," others tend to take notice and even stare (Balakrishnan, Hashim & Gao, 1999). Bernstein et al. (1988) theorizes that the stigma reaction experienced by individuals who are different in appearance is a result of an innate human response that perceives any threat to genetic heritage as a hazard, with the resulting scrutinization being a form of self-protection. Whatever the reason, our society is hesitant in accepting individuals whose appearance is "different," whether it be from visible scarring, physical restrictions or psychological impairments (Blumenfield & Schoeps, 1992).

Community Reintegration

According to Esselman et al. (2001), community integration "refers to an individual's ability to be active in his or her expected community role at home, participating in both leisure activities in the community and in productive activities such as work, school or volunteering" (pg. 221). Using the Community Integration Questionnaire (CIQ, developed by Willer, Ottenbacher & Coad, 1994), Esselman et al. (2001) found that CIQ scores in a burn population did not improve significantly over the two year examination period, but most did

improve gradually, with the improvement in Productivity scores approaching a statistically significant level. A notable stability across patients was discovered in that individual with the highest scores at the first measurement point tended to yield the highest scores at subsequent measurement times. Also found was that community integration scores in general were lower for this burn sample than in non-injury samples.

Some important patterns emerged in Esselman et al.'s 2001 study using the CIQ. Scores involving gender, living and marital status, Functional Independence scores and the TBSA involvement of the burn were all related to Home Integration outcomes. Likewise, the best predictors of Social Integration were functional scores, TBSA involvement and marital status, with those individuals who were married reporting lower scores in general. The components most closely related to Productivity scores were age, injury and work-related. Overall it appears that while individuals may resume basic functional activities rather quickly, community reintegration may tend to be reestablished gradually over a more extended length of time (Cromes & Helm, 1999).

Vocational Issues

Some of the most common problems reported by individuals at 1 year post-trauma are associated with adjustment problems, not only emotionally, but also vocationally (Wrigley, Trotman, Dimick & Fine, 1995; Fauerbach et al., 2001). According to the World Health Organization (1980), impairment involves an abnormality or loss that is psychological, physiological, anatomically structural or functional in nature. The American Medical Association (1995) defines a permanent impairment as an injury or loss that has become stabilized for a sufficient period of time to allow for optimal tissue repair and,

despite further medical or surgical therapies, is unlikely to change. A disability is described as the alteration of an individual's capacity to attend to personal, social or occupational requirements due to the sustained impairment. These concerns and others must be addressed before an individual can successfully return to work.

Recovery Period

There is often an extended recovery period with burn trauma, with TBSA involvement being the primary predictor of time elapsed before return to work (Helm & Walker, 1992). Other factors influencing time off work include the TBSA with full thickness burns, the TBSA with partial thickness burns, the presence of burns to the hands and whether the individual was employed or unemployed at the time of the injury (Helm & Walker, 1992; Bowden, Thomson & Prasad, 1989). Also age was a significant factor impacting time off work, with older individuals taking increasingly longer time to return to employment (Bowden et al., 1989). According to Ng et al. (1991), 89.6% of their study population was able to return to their previous employment; however, the average time lost from work was 85 days. These findings are corroborated by Esselman et al. (2001) in their review of existing return-to-work literature in which they report the average time off work following a burn injury to be 12 to 17 weeks. Although the desire to return to work remains unchanged (Andreasen & Norris, 1972), many individuals discover that, when they are ready to return to work, undesirable revisions such as job reassignment, changes in occupational status or issues involving functionally limited work time must be addressed (McNulty, 2002).

Return to Work

There are many factors that can significantly impede an individual's ability to return to work, even though the individual may appear capable of performing tasks necessary for employment. Tolerance to heat and cold can be restrictive in terms of the discomfort involved, as can exposure of the skin to the sun or chemical agents. Limited range of motion in one or more joints, impaired hearing, diminished hand functioning and inadequate functional independence can all be secondary complications that must be addressed. Likewise, concerns with postburn appearance as well as with issues of fatigue, poor concentration, impaired stamina, intolerance for standing or walking, decreased grip strength and deficiencies in upper extremity skills can all have a negatively limiting effect on vocational possibilities as well as on job performance. The overall psychological adaptation of an individual must be considered and in cases where the injury was sustained in the workplace, fear of returning to the site and its accompanying reminders of the trauma may pose some concern (Cromes & Helm, 1999; Helm & Walker, 1992; Cheng & Rogers, 1989).

Wrigley et al. (1995) reported the single best predictor of post injury work status is employment status prior to sustaining the burn injury. In fact, "premorbid employment accounted for a person being 171 times more likely to return to work than those who were not employed before injury" (pg. 449). Additionally, a common predictor regarding return to work after a burn injury is the individual's satisfaction with employment preburn (Esselman et al., 2001).

As was discussed earlier, both preburn psychiatric problems as well as a history of drug and alcohol abuse are predictors of increased complications during early recovery and are often precursors to long-term postburn adjustment difficulties (Kelley & Lynch, 1992; Grobmyer et al., 1996). These, along with other common barriers such as prior disabilities,

comorbid physiological illnesses and preburn unemployment, all affect treatment outcomes and impact both quality of life and the ability to return to work (Fauerbach et al., 1996; Wrigley et al., 1995). Fauerbach et al. (2001) found that individuals who were unemployed prior to the injury were more likely than employed persons to be alcohol dependent (36% vs. 18%), to abuse drugs (22% vs. 10%), to have experienced psychiatric problems requiring treatment within the past year (21% vs. 6%) and to have preburn physiological impairments (23% vs. 3%). Concomitantly, the unemployed population not only exhibited more comorbid medical problems, but also manifested a higher rate of burn-related problems than did those who were employed at the time of the injury.

Assessing Functional Assets and Limitations

Both functional assets and limitations must be assessed before the individual's potential for returning to employment is decided. If return to work is not deemed feasible, the need for job retraining or for assistive technology must then be considered. Other possible concerns involve the need for environmental accommodations or even job development (McNulty, 2002). Bowden et al. (1980) reported that over 80% of respondents stated their burn injury had caused them problems on the job. Other researchers have found that 50% to 60% of persons with burn injury required some type of change in vocational status such as job position or number of hours worked (Andreasen & Norris, 1972; Blades et al., 1979; Chang & Herzog, 1975). In cases where injuries and their ensuing functional limitations are extensive enough to prevent the individual from sustaining employment, permanent disability must be determined (Cromes & Helm, 1999). However, given adequate time to recover and rehabilitate, between 70% and 80% of individuals do ultimately return to work (Chang & Herzog, 1975; Helm & Walker, 1992).

SUMMARY

Stemming from the extensive medical advances made in the last four decades regarding the understanding and treatment of burns, there has been a significant reduction in burn injury mortality rates in the United States and an increase in burn morbidity and rehabilitation issues. A large portion of the improvement in burn injury outcomes can be attributed to the development of specialized treatment facilities or burn centers.

Because of the low survival rate involved in burn injury prior to the 1960s and 1970s, there was virtually no documentation regarding the long-term functional or psychological outcomes of burn survivors. However, subsequent research has begun to evaluate the factors that seem to contribute to positive or negative outcomes at different stages of the recovery process. Research findings have noted that both the physiological and psychological aspects of the individual are of equal importance, as neither exists as an isolated entity, but rather interacts to affect treatment outcomes. This awareness has caused the implementation within the burn care community of the biopsychosocial treatment model in which all facets of the individual's functioning are addressed. This paradigm change has led to interest in quality of life, not just survival, as an important outcome criterion.

One of the most important determinants of post-injury adjustment is premorbid functioning. Individuals with preburn psychiatric difficulties, especially depression, personality disorder and substance abuse, tend to be at increased risk of sustaining a burn injury and are overrepresented within the burn population. These complications not only increase the likelihood of sustaining a burn injury, but can negatively impact functioning during hospitalization, recovery and long-term rehabilitation.

Another of the most salient determinants of postburn adjustment is a support network. Often, especially in the event of visible scarring or disfigurement, adaptation will depend, at least in part, on the individual's ability to conceptualize his or her identity primarily on internal non-physical qualities rather than on external appearance and the reaction of others. Given the psychosocial issues encountered during recovery, external support is of vital importance in long-term recovery as the source of assistance shifts from the trained professionals in the hospital setting to family, friends and co-workers.

For a large majority of the burn population, although they must confront multiple stress factors, most symptomatology is transient in nature and subsides over time. Various studies have indicated that by two years post-trauma, most burn survivors had resumed preinjury levels of functioning in the areas of work, recreation, social and family relationships. Given adequate time to recover, the large majority of individuals in the burn population ultimately do return to work of some kind.

Anxiety, depression and pain are common areas of concern within the burn population. The presence of these factors can lead to an increased likelihood of problems in social relationships and community re-entry. Likewise, acute uncontrolled pain can not only lead to chronic pain, but maintain a traumatized state which can delay wound healing and directly impact postburn adaptation. Of primary importance is the fact that any type of mood disorder can interface with other aspects of functioning, thereby influencing overall recovery.

Adjustment problems often become apparent in the post-acute time period after hospital discharge. Many individuals may not meet the full criteria necessary for a psychological diagnosis, but they nonetheless may experience sufficient symptomatology to be considered an expression of psychopathology. As a rule of thumb, if an individual's

symptoms cause sufficient distress to interfere with his or her functioning and quality of life, the issues need to be addressed so as not to inhibit other facets of recovery.

Employability and the impact of sustained impairments on individuals vocationally is also of major concern. Studies have designated TBSA involvement as the primary predictor of time lost from work and have identified pre-injury employment status and job satisfaction as being the best indicators of an individual's post-injury work status.

After a review of the current literature it appears that functional outcomes, psychological adjustment and community integration are all major determinates of long-term quality of life outcomes in burn survivors and, for the most part, all tend to improve with time. While there is a plethora of literature discussing burn outcome studies from discharge to 12 months, there becomes progressively less and less information available for longer time periods, and what is present is often inconsistent. The following study will address this shortcoming by analyzing a sample of burn-injury patients over a period of 36 months.

The purpose of this study is to determine if statistically significant improvements in psychological well-being, overall quality of life, functional abilities, and community integration are being experienced by participants three years after burn injury. Also of interest is the impact that levels of psychological distress have on both functional ability and community reintegration in individuals with major burn injury.

It is hypothesized that adults with major burn injury will experience improvement in psychological, quality of life, and community re-entry variables from the time of hospital discharge to 3 years after the burn injury. It is also hypothesized that better functional ability and community integration will be related to lower psychological distress.

CHAPTER THREE

Methodology

Subjects

Participants in this study were adults (14+ years of age) who sustained a burn injury of sufficient severity to meet the American Burn Association's criteria for a major burn. In order to be considered a major burn, wounds must involve one or more of the following: partial thickness burns with TBSA involvement of more than 25% in adults and more than 20% in a child; full thickness burns with more than 10% TBSA; smaller burns with complicating features such as extremes in age (<5 or >60); burns to the hands, face, perineum or feet; the presence of chronic alcohol abuse or drug addiction; inhalation injury; significant preexisting medical disease or associated trauma (Shires, 1985). The subjects in this study were chosen from individuals who were admitted to a major regional burn center in a large urban metropolis which administers treatment to a distinctly diverse population. Initial sample size was 356 burn patients. All subjects agreed to participate in a federally funded longitudinal study of individuals who sustained major burn injury, and informed signed consent was obtained from each subject.

To complete an analysis of how emotional distress impacts functional recovery, the study participants were split into two groups according to their self-reported level of emotional distress. High vs. low levels of distress were determined by median split of scores (BSI-GSI and BSI-PSDI) at each measurement interval.

Data Collection

Standard variables were collected from the study participants, such as age, gender, ethnicity, marital status, educational level and employment. Burn characteristics such as TBSA, burn etiology and physical location of burn injury were also recorded, as well as disposition status and treatment characteristics.

In this study, emotional distress, pain, functional ability, quality of life, and community re-integration were measured using self-report questionnaires: the Brief Symptom Inventory, Burn Specific Health Scale, Pain Analog Scale, Functional Assessment Screening Questionnaire, and Community Integration Questionnaire. These measures were given to study participants in the form of packets they agreed to complete. All instruments were available in English and Spanish. For individuals with low reading skills, information was obtained orally with the questions being read to them. Data were collected at the time of hospital discharge and at 2, 6, 12, 24 and 36 months. In the event that participants' appointments did not coincide with a collection interval, appropriate questionnaires were either mailed or telephone calls were made to collect the necessary data. Two self-report measures (the Burn Specific Health Scale and Community Integration Questionnaire) were not collected at discharge, but were at all other intervals.

Instruments

Brief Symptom Inventory (BSI)

The Brief Symptom Inventory (BSI) is a self-report questionnaire that indicates current emotional status. It consists of 53 items that are rated on a Likert-type scale from 0 (no

distress) to 4 (extreme distress). The BSI yields 9 specific clinical scales and three summary scales as follows: Global Severity Index (GSI), which indicates overall distress; Positive Symptom Distress Index (PSDI), which indicates individual symptom severity; and the Positive Symptom Total (PST), which indicates the number of symptoms not marked zero. The clinical and summary raw scores are converted to *t* scores ($X=50$; $SD=10$), based on non-patient male and female norms. According to Derogatis & Melisaratos (1983), the BSI has exhibited both acceptable validity and good internal reliability as a measure of individuals' current emotional states. Derogatis & Cleary (1977) reported that the Cronbach's alpha coefficients were good for all nine subscales, varying in range from 0.71 to 0.85. Independently, Croog, Levine, Testa & Brown (1986) and Aroian & Patsdaughter (1989) reported BSI internal consistency coefficients for the GSI, PSDI and PST scales of 0.78, 0.83 and 0.80, respectively. The GSI has been described as the index most sensitive to psychological distress, with the presence of a *t* score of ≥ 63 being indicative of the presence of psychological distress adequate to require intervention (Derogatis & Spencer, 1982). The test-retest results reflect a GSI stability coefficient of 0.90, which indicates that the BSI is a reliable measure over time (Derogatis & Melisaratos, 1983).

Pain Analog Scale (PAS)

The PAS is a numeric measure used to evaluate subjective pain experience. Administered either in writing or orally, the respondents are requested to rate their level of pain from 1 (representing no pain) to 10 (excruciating pain). The pain intensity is measured as it is perceived by the individual at the current point in time. Patients also rate their pain as it was at its highest and lowest points during the prior 24 hours. These three levels are then

averaged as an estimation of the overall pain score experienced by the respondent within the last day.

Functional Assessment Screening Questionnaire (FASQ)

The FASQ is a scale consisting of eight self-report items that are scored on a Likert-type scale ranging from 1 (great difficulty) to 4 (no difficulty) and is used to measure the degree of difficulty an individual is experiencing with common daily task performance (Seltzer, Granger & Wineberg, 1982). The totaled individual item scores range from 8 to 32, with higher scores being indicative of increased perceived overall functional ability. It is important to note that this instrument is not a measure of the resumption of pre-injury functional role activities, but rather addresses the perceived ability to perform tasks presently (Cromes, Holavanahalli, Kowalske & Helm, 2002). According to Seltzer, Granger & Wineberg (1982), both the validity and internal reliability of the FASQ are acceptable.

Burn Specific Health Scale (BSHS)

The BSHS was originally developed at the Baltimore Regional Burn Center in response to the increasing awareness of the need for a measure other than survivability that could evaluate the outcomes and effects of burn therapy on individuals who survived major burns. Consequently, the goal of this team of researchers was to develop a way by which a burn survivor's quality of life might be measured. The motivation to conscript such a measure was based on the theory that in order to adequately address the outcomes of individuals with burns, studied data must afford researchers a "comprehensive view of the individual as a system with psychological, social and physical components, each of which must be considered in the evaluation of outcome" (Blades, Jones & Munster, 1979, pg. 556).

Several years later, an abbreviated version of the BSHS was developed (Munster, Horowitz & Tudahl, 1987).

The BSHS is a self-report questionnaire that includes 80 items rated on a Likert scale with responses ranging from 0 (extreme difficulty) to 4 (the absence of difficulty), with higher scores signifying better adjustment or quality of life (Blades, Mellis & Munster, 1982; Munster, Horowitz & Tudahl, 1987; Fauerbach et al., 1996). The results are calculated by dividing the total score by the total possible score, thus yielding an index ranging from 0.00 to 1.00. The BSHS results in a Global Domain or total score as well as scores in the Physical, Psychological, Social and General Domains. The Physical, Psychological and Social Domains also contain sub-domain scores, i.e. role activities, mobility, self care and hand function within the Physical Domain; body image and affective issues within the Psychological Domain; and issues with family/friends and sexual functioning within the Social Domain. The General Domain measures emotional factors associated with burn sequelae like pain, appearance and social interactions.

According to Munster et al. (1987), evaluation of the reliability and validity of the measure have suggested that the BSHS has sound psychometric properties. Fauerbach et al. (1996) reported that with domain alphas ranging from 0.86 for the physical subscale to 0.92 for the psychological subscale, the internal consistency appeared good. They also noted that criterion-related validity coefficients at the $P < 0.05$ level ranged from 0.60 on the physical subscale to 0.78 for the mental subscale, and that at the $P < 0.001$ level, one-week retest reliability was good at 0.89.

Community Integration Questionnaire (CIQ)

Willer, Ottenbacher & Coad (1994) developed the Community Integration Questionnaire (CIQ), a measurement tool designed to assess the multiple aspects of community integration, in response to the need for a comprehensive measure of social and community reintegration outcomes within trauma populations. While the Community Integration Questionnaire (CIQ) was intended to be a brief, reliable measure of the achieved level of integration into the home and community, it is important to recognize that this instrument represents a finite set of indicators of community integration, and as such is not intended to comprise all possible facets of integration (Burleigh, Farber & Gillard, 1998). The authors used design criteria that were intended to maintain brevity while being suitable for use in either an in-person or telephone interview, conducted with the impaired person or with a proxy (Willer, Ottenbacher & Coad, 1994). The instrument was also designed to focus on behaviors rather than feeling states while avoiding biases resulting from age, gender or socioeconomic status and being sensitive to a wide variety of living situations.

The CIQ is a self-report, 15-item questionnaire that provides a total score and scores for Home Integration (H), Social Integration (S) and Productivity (P) (Esselman et al., 2001; Burleigh, Farber & Gillard, 1998). The scoring is primarily based on the frequency with which the activities or roles are performed, with secondary weight given to whether or not they are performed alone or jointly with others, and the nature of the other persons with which they are executed. In its current format, the CIQ can be completed in about 15 minutes. The most common method of data collection is either self-administration or in-person interview; telephone interviewing is also quite common (Burleigh, Farber & Gillard, 1998). According to the authors, the subscale reliability coefficients vary from 0.83 to 0.97 with subscale test-retest reliability coefficients ranging from 0.91 to 0.97 (Dijkers, 1997).

Statistical Procedures

Changes over time were measured using a repeated measures ANOVA and results at different time intervals were compared using a Bonferroni Multiple Comparison Test. FASQ and CIQ total scores for individuals exhibiting high versus low measures of emotional distress (with median split of BSI global scores) was compared at each measurement period using the Student's T-test. A $p < .05$ criterion was established in order to conclude statistical significance.

CHAPTER FOUR RESULTS

Demographic Characteristics of Study Sample

Data was collected from 356 participants at the time of discharge from the hospital, 199 participants at 2 months, 225 participants at 6 months, 193 participants at 12 months, 114 participants at 24 months, and 41 participants at 36 months. The study subjects were predominantly male, with the average overall age of the respondents being 36.7 years. Sixty-three percent of the population were Caucasian, 20% were African American, 15% were Hispanic, and less than 2% were other ethnicities. It should be noted that while there was significant change in sample size due to attrition, the results remain valid in view of the fact that across time the sample characteristics did not change significantly. These data across the measurement periods can be observed in Table 4-1.

Burn Characteristics of Study Sample

Total Body Surface Area (TBSA)

As shown in Table 4-2, the percentage of Total Body Surface Area (TBSA) burn across the measurement periods ranged from 22.4 ± 15.7 at the time of hospital discharge ($n = 356$) to 25.2 ± 13.5 at 36 months ($n = 41$). The TBSA percentages vary considerably (note standard deviations) because the definition of severe burn injury that was an inclusion criterion for this sample, includes small burns of the face, hands or perineum as well as very large burns.

Table 4-1. Demographic Characteristics of Study Participants.

Characteristics	Discharge	2 months	6 months	12 months	24 months	36 months
	(n=356)	(n=199)	(n=225)	(n=193)	(n=114)	(n=41)
	% or Mean±SD	% or Mean±SD	% or Mean±SD	% or Mean±SD	% or Mean±SD	% or Mean±SD
Age at Injury	35.9±13.2	36.9±13.6	37.2±13.7	37.4±13.8	36.8±13.4	36.2±12.9
Gender:						
Male	82.9%	82.4%	81.8%	81.3%	83.3%	78.0%
Female	17.1%	17.6%	18.2%	18.7%	16.7%	22.0%
Ethnicity:						
Caucasian	63.5%	63.8%	63.1%	63.7%	61.4%	63.4%
Afr-Amer	18.0%	17.6%	18.7%	19.7%	22.8%	24.4%
Hispanic	16.3%	17.1%	15.1%	15.5%	14.0%	12.2%
Other	2.2%	1.5%	3.1%	1.1%	1.8%	0.0%

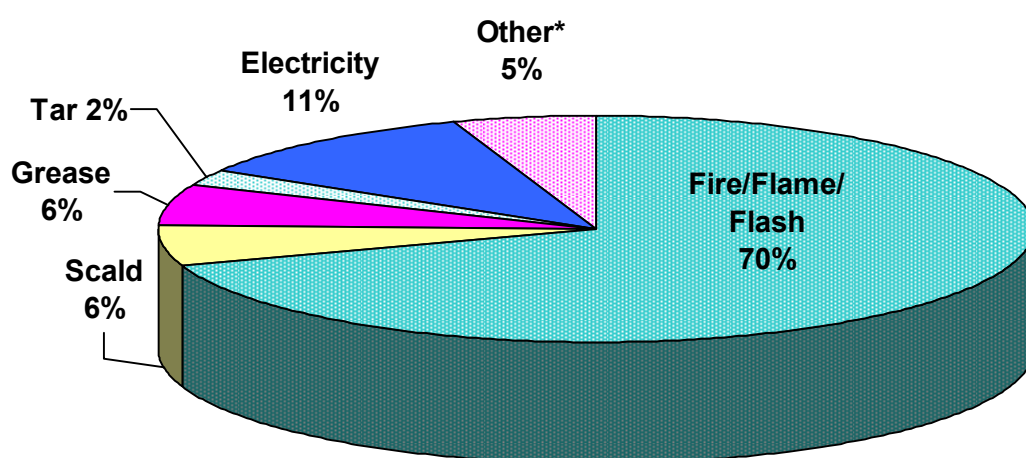
Table 4-2. Total Body Surface Area (TBSA) of Burn of Study Participants Across Study Time Intervals.

	Discharge	2 months	6 months	12 months	24 months	36 months
	(n = 356)	(n = 199)	(n = 225)	(n = 193)	(n = 114)	(n = 41)
	Mean ± SD					
TBSA	22.4 ± 15.7	22.3 ± 15.9	24.9 ± 16.2	24.8 ± 16.8	24.7 ± 15.0	25.2 ± 13.5

Burn Etiology

The primary cause of burn injury in this study population was fire (70%). Electrical burns (11%) were the next most common cause of burn injury among the participants in this study. Etiology of burn for the entire sample is shown in Figure 4-1.

Figure 4-1. Distribution of Study Sample by Etiology of Burn Injury.



*The "Other" category includes: contact with hot object, chemical, TENS, abrasions, hydrochloric acid, and unknown.

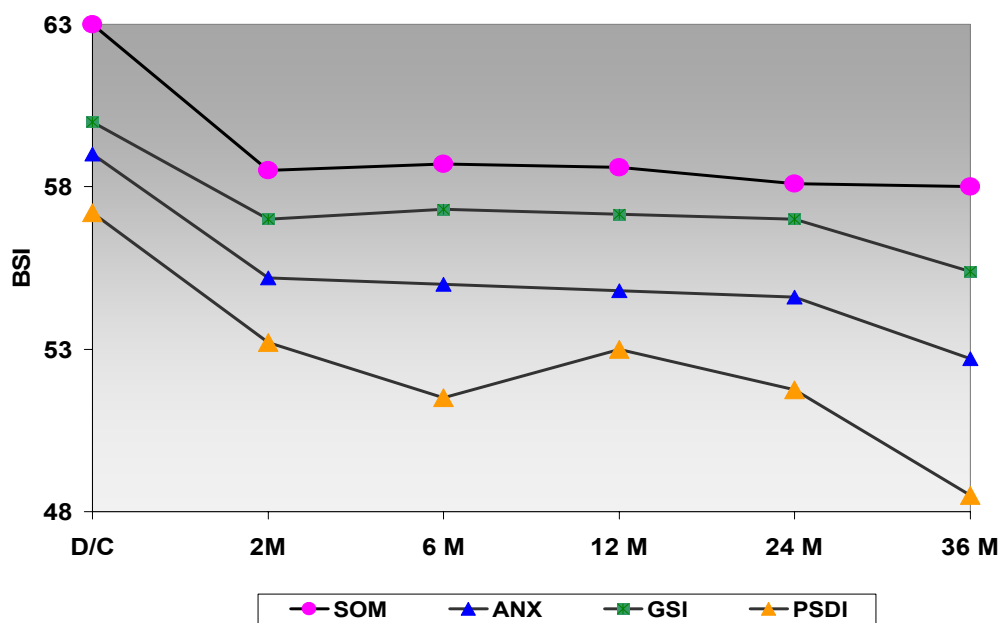
Outcomes Over Time

Brief Symptom Inventory (BSI)

Emotional distress was measured with the Brief Symptom Inventory (BSI). The significant changes over time can be observed in Figure 4-2. In this study, significant changes were found in the Somatization (SOM) dimension ($p < .0001$), which reflects

psychological distress arising from perceived bodily dysfunction. There was also a significant decrease in anxiety (ANX) symptoms ($p < .0001$) which include restlessness, nervousness, tension, and experiences involving free-floating anxiety & panic. The Global Severity Index (GSI), which was used to measure overall emotional distress ($p < .01$) and the Positive Symptom Distress Index (PSDI) which indicated the intensity of perceived psychological distress ($p < .0001$) both manifested significant improvement over time. These changes were most pronounced between discharge and 2 months post discharge and thereafter remained stable. There were no significant changes across the time intervals for the other BSI scales.

Figure 4-2. Scores on the Brief Symptom Inventory (BSI) Indicating Changes Over Time in Somatization, Anxiety, Global Severity Index and Positive Symptom Severity Index.



SOM = Somatization

GSI = Global Severity Index

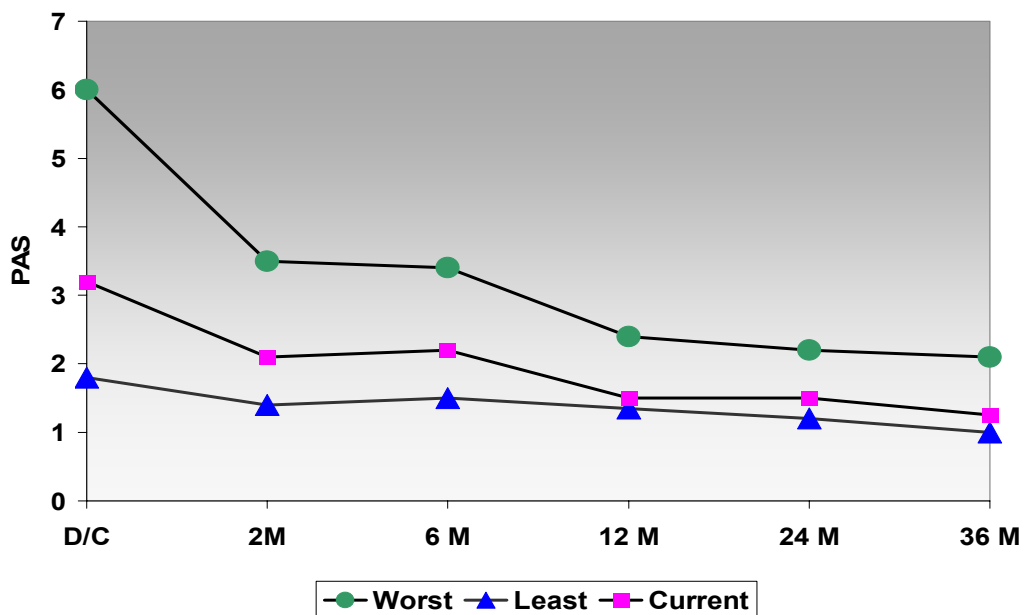
ANX = Anxiety

PSDI = Positive Symptom Distress Index

Pain Analog Scale (PAS)

The Pain Analog Scale (PAS) is designed to evaluate subjective pain experience. Three ratings were collected: the worst pain and the least pain in the last 24 hours and the current level of pain. Statistically significant changes were found in each of the three categories ($p < .0001$) from the time of discharge until 2 months postburn. Pain levels continued to decrease until 2 years postburn, and thereafter stabilized. Changes in pain ratings over three years are shown in Figure 4-3.

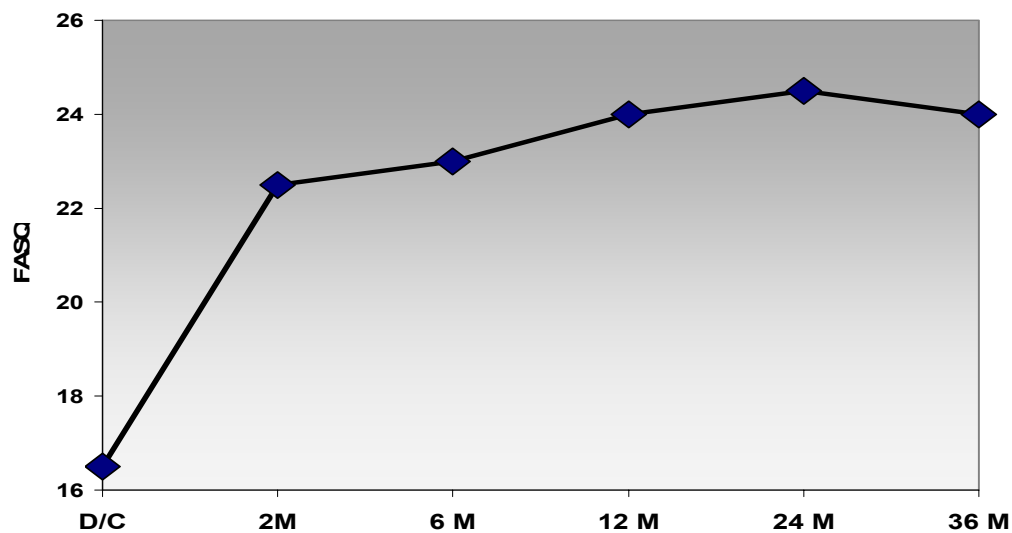
Figure 4-3. Change Over Time Intervals in Least, Worst and Current Pain Scores on the Pain Analog Scale (PAS)



Functional Assessment Screening Questionnaire (FASQ)

Significant improvement was found in self-reported functional ability between hospital discharge and 2 months postburn ($p < .0001$). The majority of improvement occurred during the first two months after discharge, with residual amounts of improvement thereafter. The FASQ is designed to measure functional ability in common daily task performance. It is important to note that this instrument is not designed to be a measure of the resumed pre-injury functional ability, but rather to be a measure of the present perceived ability to perform tasks. Figure 4-4 illustrates changes in FASQ scores from the time of hospital discharge to three years post-burn.

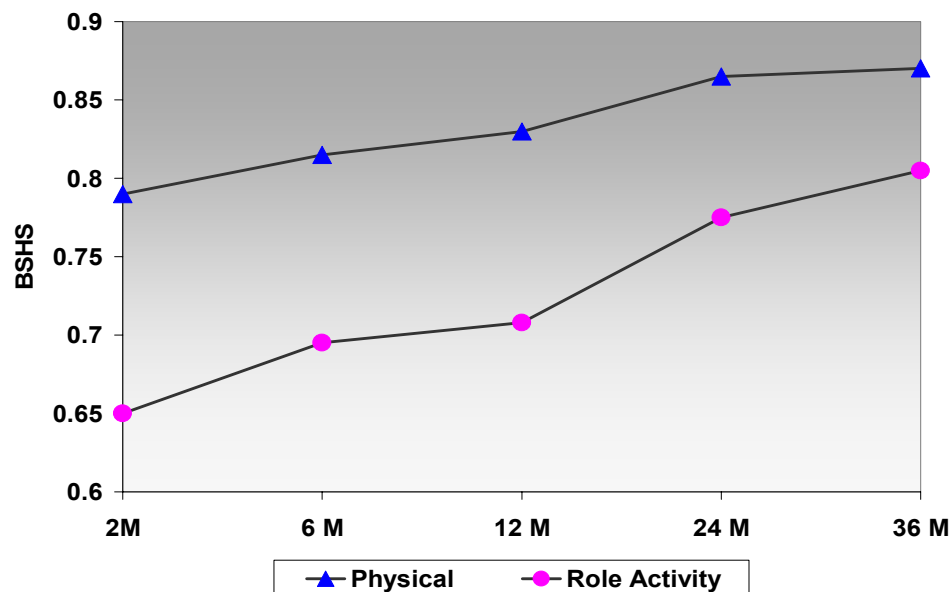
Figure 4-4. Improvement in Functional Ability over Time as Shown by Scores on the Functional Assessment Screening Questionnaire (FASQ)



The Burn Specific Health Scale (BSHS)

The Burn Specific Health Scale (BSHS) is designed to measure issues related to quality of life. Significant changes over time were found in the Physical Domain ($p < .05$) which addresses such aspects as mobility, self care and role activity. Within the Role Activity Sub-Domain, which specifically addresses performance of duties on the job or in the home, there were also significant improvements in functioning ($p < .01$). Changes in both the Physical Domain and in Role Activity were most pronounced between 2 months post discharge and 2 years postburn, remaining stable thereafter. These changes over time are reflected in Figure 4-5. There were no significant changes across the time intervals for the other BSHS domains.

Figure 4-5. Improvement in Functional Ability over Time as Shown by Scores on the Burn Specific Health Scale (BSHS)



Community Integration Questionnaire (CIQ)

The Community Integration Questionnaire (CIQ) accesses multiple aspects of community integration and is intended to be a comprehensive measure of social and community reintegration outcomes within trauma populations. It is also designed to focus on behavior rather than feeling states. Results reflected statistically significant change in both the Productivity Scale ($p < .0001$) and the CIQ Total scores ($p < .0001$) between 2 months post discharge and 24 months postburn. Scores dropped slightly between 24 and 36 months. There were no significant changes across time intervals for the other CIQ scales. (See Figures 4-6 and 4-7.)

Figure 4-6. Total Scores on the Community Integration Questionnaire (CIQ)

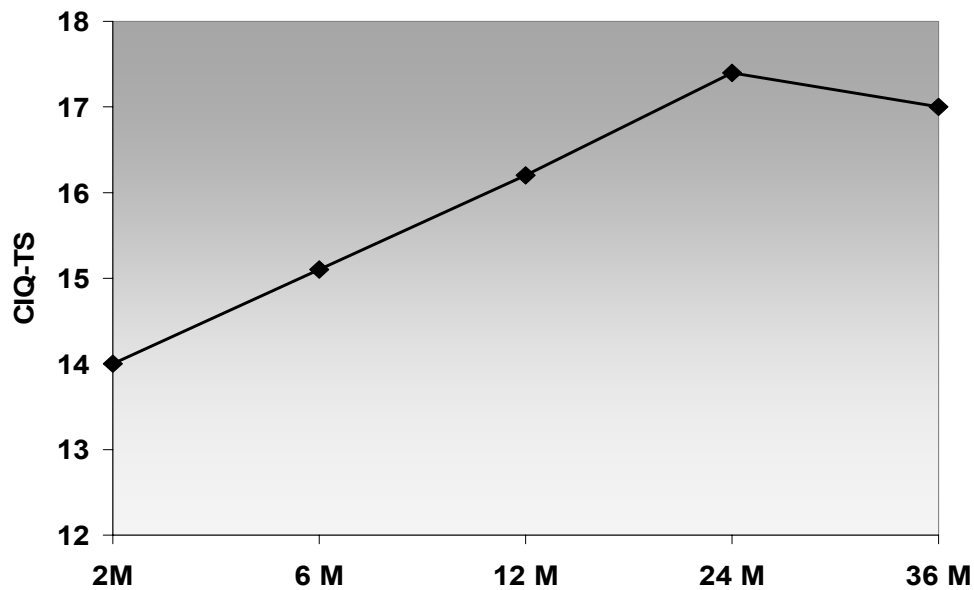
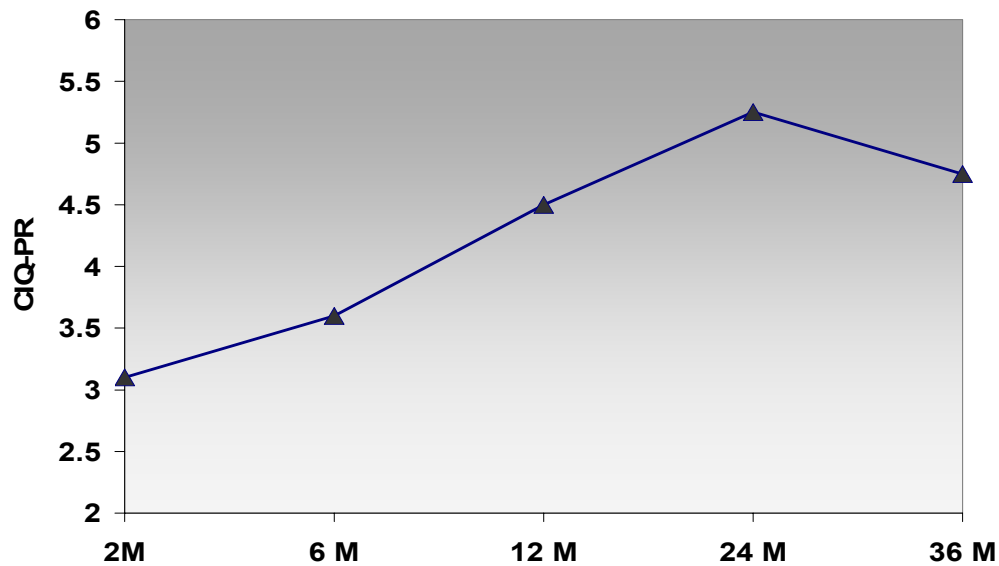


Figure 4-7. Productivity Scores on the Community Integration Questionnaire (CIQ)



Relationship Between Functional Ability and Level of Emotional Distress

It was hypothesized that better functional ability and community integration would be related to lower psychological distress. To test this hypothesis, the sample was divided into “high distress” and “low distress” groups based on their scores on the BSI (a) Global Severity Index (GSI) and (b) Positive Symptom Distress Index (PSDI). (See Table 4-3 for the median values and range.) For both measures of emotional distress, individuals with high emotional distress were defined as those who scored above the median. Individuals with low emotional distress were defined as those who scored below the median. These high and low distress groups were then compared using the Functional Assessment Screening Questionnaire (FASQ) to ascertain whether level of emotional distress was related to basic functional ability.

Table 4-3. Median Split of High-Distress and Low-Distress Groups on BSI-GSI and BSI-PDSI at each Follow-Up Interval

Follow up Interval	BSI-GSI		BSI-PDSI	
	Median Values	Min – Max Values	Median Values	Min – Max Values
Discharge	60.00	33-80	59.00	22-80
2 months	57.00	33-80	54.00	22-80
6 months	57.00	35-80	54.00	22-80
12 months	58.00	33-80	53.00	22-80
24 months	55.00	35-80	53.00	22-74
36 months	59.00	33-80	54.00	22-68

Note. On the BSI, higher scores are indicative of more distress.

Data from this study showed that individuals exhibiting lower overall emotional distress on the BSI-GSI had statistically greater functional ability than those experiencing higher levels of emotional distress. Statistically significant differences were found at discharge through 6 months ($p < .0001$) and also at 12 months ($p < .01$). (See Figure 4-8.)

Similarly, when emotional distress was defined by the BSI-PDSI, individuals with lower levels of emotional symptom intensity showed greater functional levels than those with higher emotional distress. Self-reported functional ability significantly improved at all measurement intervals up to 24 months ($p < .05$ to $.001$). Compared to individuals reporting high emotional symptom intensity distress, the low distress group in this study exhibited statistically higher functional abilities at discharge through 6 months ($p < .0001$) and also at 12 months ($p < .01$), with scores stabilizing thereafter. (See Figure 4-9.)

Figure 4-8. Improvement in Functional Ability (FASQ score) among Burn Patients with High and Low Emotional Distress (BSI-GSI score)

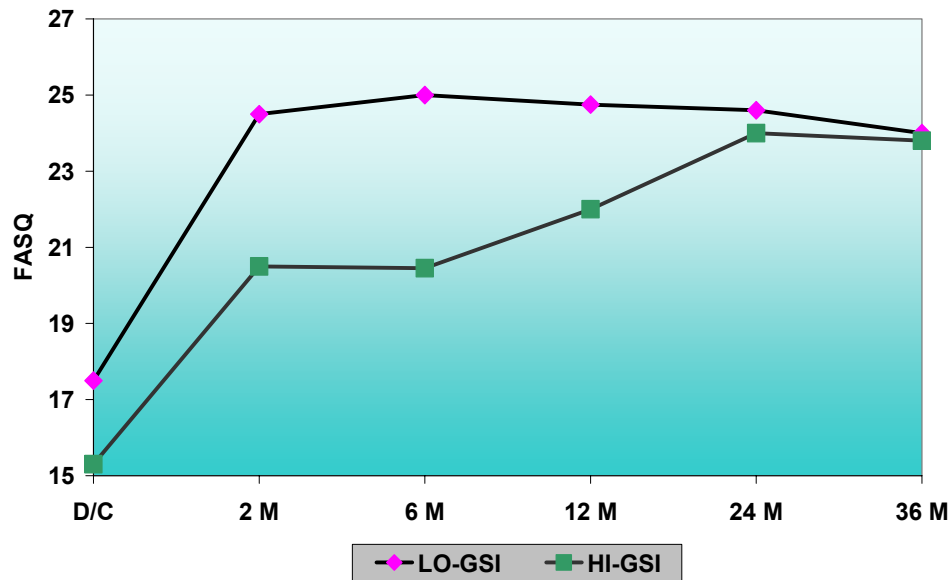
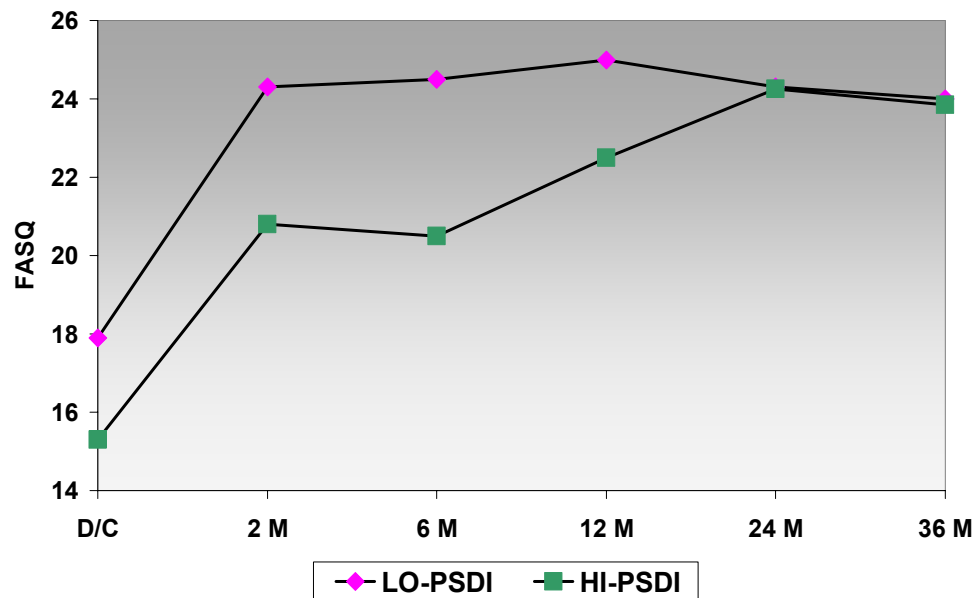


Figure 4-9. Improvement in Functional Ability (FASQ score) among Burn Patients with High and Low Psychological Distress (BSI-PSDI score)

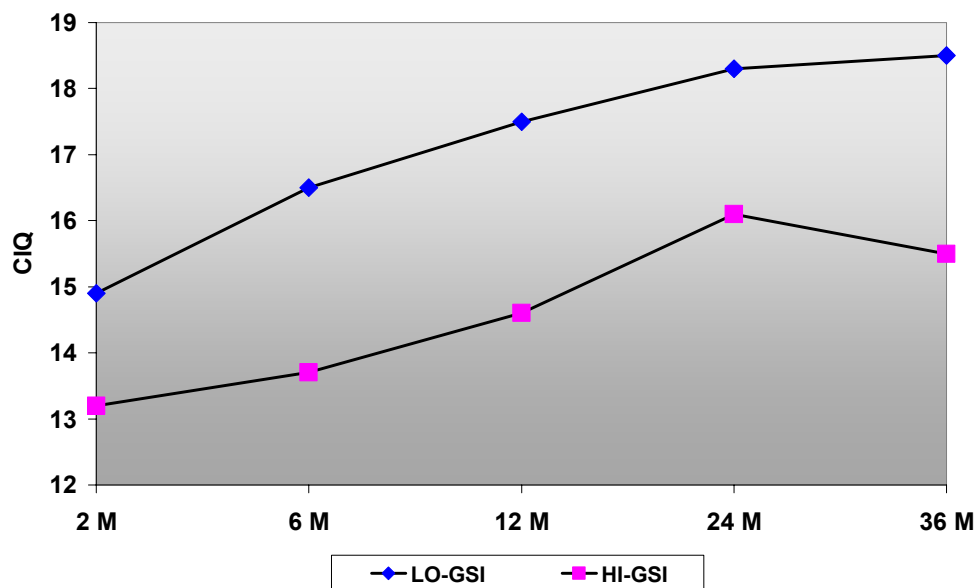


Relationship Between Community Integration and Level of Emotional Distress

The sample was divided into high-distress and low-distress groups based on their BSI-GSI and BSI-PDSI scores. These high and low distress groups were then compared using the Community Integration Questionnaire (CIQ) Total Score to ascertain whether level of emotional distress was related to community integration issues.

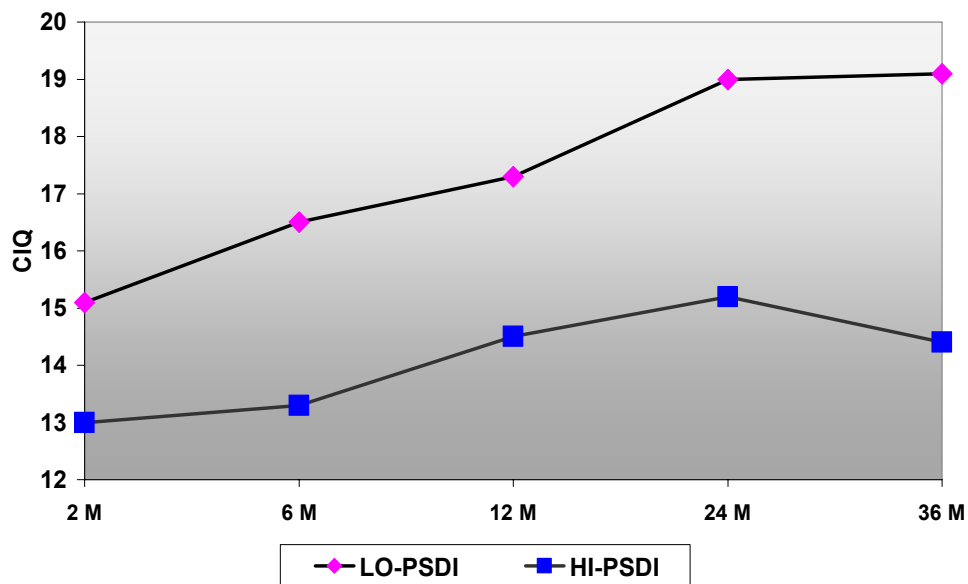
When emotional distress was defined using the BSI-GSI, there were significant differences between the groups. Decreased community integration was observed at statistically significant levels in individuals reporting greater emotional distress at 2 months ($p < .05$), 6 months ($p < .001$) and 12 months ($p < .01$), thereafter stabilizing. (See Figure 4-10.)

Figure 4-10. Improvement in Community Integration (CIQ score) among Burn Patients with High and Low Emotional Distress (BSI-GSI score)



When emotional distress was defined using the BSI-PDSI, significant differences were again noted. Among individuals with lower emotional symptom intensity distress, self-reported community re-integration was higher at all measurement intervals up to 24 months ($p < .05$ to $.0001$). Problems in community re-integration were observed for a longer time period in participants reporting higher levels of distress in the BSI-PDSI group than for any other group measured (See Figure 4-11.)

Figure 4-11. Improvement in Community Integration (CIQ) among Burn Patients with High and Low Psychological Distress (BSI-PSDI score)



CHAPTER FIVE

Discussion

There were two important findings in this study. The first finding is that the rehabilitation from burn injury appears to occur sequentially with some factors improving quickly and others improving more slowly. This tends to support the Faber et al. (1987) theory that recovery from burn injury is both dynamic and cyclic in nature. The second important finding in this study relates to the importance of psychological distress – specifically, symptoms of anxiety such as restlessness, nervousness, tension and free-floating anxiety or panic as well as distress arising from awareness of bodily dysfunction as uniquely perceived by the individual patient – as a mediating factor in the community re-integration process. This substantiates a plethora of findings such as that of Wiechman et al. (2001) in which treatment outcomes are deemed to be affected by both physical and psychological problems. This study has provided valuable findings in areas considered of importance by such prior research as Patterson et al. (2000) who stated that rather than one specific factor, an interaction of biological, psychological and social factors impact treatment outcomes. Logically, research that gathered data over more extensive time intervals could be expected to generate valuable treatment information as even early literature such as Andreasen et al. (1972), Blades, Jones & Munster (1979), Chang & Herzog (1975) and Sheffield et al. (1988) reported morbid dysfunction as becoming most apparent within the first year posttrauma.

It was hypothesized that adults with major burn injuries would experience improvement over time in emotional status, functional ability and community re-entry variables from hospital discharge to three years postburn injury. The data supported this

hypothesis which also confirmed the findings by Patterson et al. (1993) indicating that while the initial impact of burns may be severe, the long term effects may prove minimal. According to data gathered for this study, the initial 2 months post discharge is a crucial time during which the BSI scores indicated significant decreases in overall emotional distress levels (BSI-GSI) and symptomatic intensity (BSI-PSDI). This suggests that many individuals who sustain burn injury may experience significant levels of postburn emotional trauma, especially in the two months after discharge. This supports the findings of Ward et al. (1987) who stated that even individuals who are apparently well adjusted can experience emotional distress posttrauma. However, this same study pointed out the fact that it the best predictor of postburn distress lies with the individual rather than the injury and that a history of emotional problems tends to exacerbate the likelihood of postmorbidity emotional problems. Likewise, Patterson, et al. (1993) reported that emotional symptoms, although common in the burn population, are often transient in nature.

Findings within the BSI clinical scale scores indicated the presence of significant levels of anxiety (ANX) as well as other psychological symptomatology stemming from the individual's perceived bodily dysfunction (SOM). These increased level of anxiety outcomes tended to validate the Madianos et al. (2001) study which reported anxiety as one of the significant factors in individuals with burn injury at the measurement intervals of 3 weeks and 12 months postburn. However, unlike this current study which showed significant decreases in anxiety levels by the 2 month time interval, the Madianos et al. (2001) study reported a less than 5% reduction in distress levels between the measurement intervals. Blumenfield & Schoeps (1992) theorized that the trauma of having confronted the possibility of imminent death may have produced such marked anxiety in an individual that it may remain long after the physical wounds healed. With attention initially on maintaining

survivability (Avni, 1980) and addressing pathophysiological concerns such as adequate fluid replacement, the treatment of smoke inhalation and guarding against infection (Heimbach, Engrav & Marvin, 1981), a burn individual's acute outcome is often precarious at best. Inasmuch as the (SOM) scale involves a discussion of health issues and physical concerns, elevated scores within this area are, of course, to be expected during the early period posttrauma when physiological outcomes and the resumption of functional capabilities are most uncertain.

It is also important to note that while BSI scores must be 63 or above to be considered clinically significant (Derogatis & Melisaratos, 1983), several of the other clinical scale scores were well above average relative to the general population score of 50. Scores on BSI clinical scales other than somatization and anxiety, although not increased enough to be of clinical significance, were however, adequately elevated to possibly merit treatment. As Weichman et al. noted in their 2001 study, though levels of distress may not clinically meet specific diagnostic criteria, they can, nonetheless be of sufficient intensity to interfere with both recovery and quality of life and should be treated accordingly.

Similarly, scores on the PAS were elevated at all three measurement levels (worst, least and current) at discharge, but reduced significantly by 2 months after discharge and thereafter remained stable. Considering the BSI findings, these results are quite understandable given the correlation between emotional distress and pain. Davis & Sheely-Adolphson (1997) reported that initially, the primary problem faced by individuals with burn injury was the attempt to cope with the acute pain involved. The current study outcomes also substantiate the findings of Patterson et al. (1993) who reported pain as playing a significant role in an individual's psychological adjustment, particularly during the acute phase of recovery when, as described by Mersky (1986) the pain tended to be acute and

severe; thereafter gradually declining. This current data also tends to support Cromes & Helm's (1999) findings that postburn anxiety or other emotional distress is often intensified by the pain of dressing changes concomitant with fear regarding dependency issues and long term consequences of the burn injury.

The present study substantiated several theories postulated in various studies regarding pain perception and recovery. McNulty (2002) stated that coping modalities are influenced by pain perception and likewise, the individual's method of coping influenced how the pain was perceived. For example, if pain was perceived as uncontrollable or unbearable then coping abilities tended to degenerate leading to more maladaptive responses such as catastrophizing or aggression. While this current study neither substantiated nor contradicted the finding of Ptacek et al. (1995), it is still interesting to note that their research results suggested that acute procedural pain immediately postburn may directly impact later adaptation outcomes. Their study identified a positive correlation between procedural pain within the first 5 days postburn and future psychosocial adjustment one month post discharge. This specific factor proved to be a more adequate predictor of future adjustment than either the size of the burn or the length of time in the hospital. It is also important to note that pain can hinder the actual healing process according to Ptacek et al. (1995) who stated that burn pain can produce a stress response, thereby maintaining a shock cycle in burn patients who are traumatized that can both delay wound healing and prolong the recovery process. Liebeskind (1991) stated that pain of sufficient magnitude can both directly and indirectly suppress the immune system. These varied studies have established a correlation between levels of pain and both emotional distress and physiological healing.

Concurrent with this improvement in emotional functioning and a significant decrease in pain levels, statistical results on the FASQ reflected an increase in functioning in common

daily tasks performance. Statistically significant levels of improvement were observed in self-reported functional ability during the first 2 months post discharge and thereafter, the levels remained stable. As the FASQ is not designed to be a measure of the resumption of pre-injury functional levels, but of the *perceived* ability to perform current tasks, the tremendous impact individual self-perception has on recovery is further delineated. As Holaday & McPhearson (1997) stated, the relinquishing of control over major areas of life to others, even for a limited time, can be perceived as devastating. Therefore, perception is so important in that some individuals, though actually functionally capable of self-care, may regress to less mature methods of coping such as appearing overly dependent for a time (Browne et al., 1985; Davis & Sheely-Adolphson, 1997). The findings of this previous research tends to support the theory that perception is a key factor in all areas of recovery whether it be emotional issues, pain intensity or improvement in functional ability (McNulty, 2002; Ptacek et al., 1995; Romano & Turner, 1985). In this current study, data corroborates the fact that with decreased pain, anxiety, and perceived bodily dysfunction, an improvement was observed in functional ability. This supports the findings of Cromes & Helm (1999), who reported that activities such as self-care can be severely constricted by acute phase problems and by medically necessary treatment procedures but tend to be self-limiting in nature and not likely to cause permanent impairment. According to Blumenfield & Schoeps (1992) it is also important not to minimize either the loss of body integrity or an individual's sense of safety and well-being in the world.

An additional focus of study regarding functional areas of recovery involved the correlation between emotional distress and functional ability. Our data indicated that individuals who experienced higher levels of emotional distress exhibited lower functional ability for up to 12 months postburn. These findings concurred with those of various

historical studies who reported finding that the majority of individuals reported a decrease in emotional symptomatology within one to two years posttrauma and were able to resume preburn functional levels with regard to work and recreation as well as interpersonal and family relationships (Chang & Herzog, 1975; Andreason et al., 1971; Andreason & Norris, 1972). The Mangus et al. (1993) study points out the fact that personality cannot be separated from functioning and therefore can strongly influence the recovery process. Other prior research suggests that pre-existing personality traits may determine how different individuals experience events in a positive or negative way (Headey & Wearing, 1989; Ormel & Schaufeli, 1991), again reiterating how strongly individual perception may influence recovery.

Results from the BSHS revealed important changes over time in overall quality of life. Our results indicated that individuals with burn injuries began to exhibit statistically significant increases in the quality of life as reflected in the Physical Domain and Physical Role Activity subdomain of the BSHS between 2 months post discharge and 2 years postburn injury. Thus, improvement in these areas was much slower to develop than reduction in emotional distress (BSI), reduction in pain (PAS), or improvement in basic functional ability (FASQ). It should be noted that no BSHS measure was taken at discharge. This measure was chosen as the quality of life measure in this study because it not only meets the criteria for a QOL measure, but is specifically sensitive to the burn population (Cromes et al., 2002).

Improvement in the Physical Domain of functioning delineates numerous areas of overall well-being including, activities of daily living such as bathing, dressing, eating and shopping, while Role Activity involves such functional abilities as doing chores at home, being involved in leisure activities, being physically active and resuming employment duties.

The finding of these improvements over time substantiates the findings of Wrigley, et al. (1995) and Fauerbach et al. (2001) who noted that one of the most common problems reported by individuals 1 year postburn involved vocational issues. Of course, there are many additional factors that impact employment other than strictly physical concerns. According to Helm & Walker (1992), TBSA involvement is a primary factor as well as is age at the time of injury (Bowden et al., 1989). Wrigley et al. (1995) reported premorbid employment as being the single best predictor of postinjury employment status. Fauerbach et al. (2001) results showed that unemployed individuals not only experienced more comorbid medical problems, but tended to manifest an increased rate of burn-related problems than did individuals who were employed.

Interestingly enough, functional improvement on the FASQ was observed in the first two months post discharge, while functional improvement on the BSHS appeared to be more gradual. One possible explanation for this finding is that the FASQ items are less complex than the functioning items on the BSHS. Since the FASQ findings are similar to the PAS findings, FASQ scores may be related to reduction in subjective levels of pain, which decrease substantially in the first two months after discharge. It is also possible that had the BSHS been administered at discharge, more rapid earlier improvement might have been observed on this measure.

As measured by the CIQ, levels of community integration and productivity also improved significantly from 2 months post discharge to 24 months postburn, remaining level thereafter. These findings support the Esselman et al. (2001) findings in which the CIQ scores improved significantly over the two year examination period with the improvement in Productivity Scores approaching significant levels. Interestingly, a notable stability was discovered among the participants in this study in that individuals with the highest scores at

the initial measurement interval also yielded the highest scores at subsequent measurement times. This again tends to suggest that self-perception may influence recovery outcomes.

However, individuals experiencing higher levels of distress (as opposed to those reporting lower distress levels) showed lower functional ability up to 12 months postburn. These subjects also exhibited lower levels of community re-integration. It is important that individuals experiencing high distress be identified at the time of discharge so that appropriate intervention can be provided. Interestingly enough, the only area in which individuals continued to exhibit significant difficulty for up to 36 months post injury were the subjects who reported higher specific emotional symptoms (PSDI) and exhibited lower levels of community reintegration. This substantiates the findings of Patterson et al. (1993) who reported that individuals who experienced emotional distress tended to withdraw socially. Bowden et al (1980) theorized that while some aspects of trauma postburn appear to subside over time, other features such as emotional adjustment tend to become evident sometimes years after sustaining the injury. Cromes & Helm (1999) sum it up best when they reported that overall, though individuals may resume basic functioning rather quickly, community reintegration may tend to be re-established gradually over a more extended length of time.

Cobb et al. (1990) stated that personal satisfaction in the pertinent areas of life such as health, leisure activities, interpersonal and community relationships and the ability to sustain a sense of productivity all interconnect to comprise an individual's quality of life. Therefore, beyond survivability, there is no single area of functioning or recovery that stands alone in importance. Rather to achieve the goal of becoming as functionally capable as possible in all areas of life is what constitutes successful recovery.

One of the most notable aspects of this study involves the focus of recovery. Nearly every factor that was of statistical significance over time was related to the physical functioning aspect of recovery. The BSI indicated distress in the area of somatization (SOM) which focuses on concerns with the body and on its perceived physical functioning; the PAS addresses pain which is also physical in nature. FASQ and BSHS measures indicated a focus on Physical and Role Activities, both aspects of which center not only on functional abilities but also on self-care and autonomy within these activities. Scores on the CIQ indicated that Productivity was the salient factor within that measure, which again focuses on physical functioning and independence.

There are several possible explanations for these findings, not the least of which is that it reflects the emphasis culturally that is placed on autonomy. These factors not only appear to be the primary focus of concern and energy, but often hold sway at the expense of emotional well being which seems to be devalued in comparison. Another factor that possibly influenced these findings is the fact that the vast majority of the study population was male. Although this more than three to one male/female representation was typical of the burn population, the results may reflect a stereotypically masculine focus on the importance of physical outcomes and capabilities over emotional functioning. Patterson et al. (1993) identified the loss of independence and the necessity of being cared for by others as a primary recovery challenge. Holaday & McPhearson (1997) found that the loss of power experienced by those who must relinquish control to others can be experienced as quite devastating to individuals who highly value autonomy.

Strengths And Weaknesses Of Study

Research to date involving the many pertinent aspects of wellbeing as identified by the biopsychosocial model of functioning — specifically, emotional distress, pain, quality of life, functional ability and community integration – has been sparse at best. Most studies using burn specific measures to determine quality of life have evaluated findings to 2 months postburn and no further (Lawrence & Fauerbach, 2002). In contrast, the current study has uniquely followed study participants for the express goal of determining what, if any, long term effects develop concomitant to the burn injury, using a variety of measures. Having taken measures at several different time intervals, specifically, at hospital discharge, 2 months, 6 months, 12 months, 24 months and 36 months post injury, this research is a particularly valuable contribution to the study of burn rehabilitation. It is one of the few longitudinal, repeated-measures studies performed to date that addresses the recovery and rehabilitation of individuals with burn injury as a multi-faceted sequential process. This design allowed a more extensive analysis of the interaction between different measures and a clearer view of the multiple aspects of recovery over a longer period, compared to previous published studies.

Another strength of the current study is its prospective nature. Prospective longitudinal designs are believed to be the most effective research designs to describe and establish the temporal order of developmental processes (Pedhazur & Schmelkin, 1991). Although participant behavior may be influenced by the act of repeated self-evaluation, repeated measurement or questioning in prospective studies has the benefit of immediacy, which minimizes problems with respondent recall (King, 2001).

Further, the analyses comparing high- and low-distress groups is unique to this study, in that groups were compared with a range of measures for physical, social and psychological outcomes. These analyses highlight the importance of emotional factors as a variable affecting all aspects of recovery for three years after burn injury.

The fact that much of the information gathered in this study relates specifically to the burn injured and the distinctive needs of this population renders these research findings of greater value in assisting these individuals toward more positive long-term recovery outcomes. While “major burn injury” was part of the inclusion criteria for this study, its findings about recovery trajectory and the interaction of biopsychosocial factors may have application to other categories of burn-injured patients.

On the other hand, our attrition rate, although comparable to other longitudinal studies conducted in this field, does somewhat limit our ability to generalize the findings to the population of individuals with major burn injury. It is not clear how the characteristics of non-completing or non-consenting patients might have affected the study results. Possibly the individuals who participated in this study, and those who completed all phases, are not representative of the population of individuals with major burn injury, but rather a higher-functioning group with the internal and external resources to continue participation through three years. This weakness may be partially attenuated by the use of newly-developed statistical procedures that can partially compensate for missing data.

Another factor that may reduce generalizability is the gender split of the study sample. There were more than three times more males than females in this study, which, although representative of the burn population ratios, nevertheless may not produce results that can be generalized to a strictly female population.

All instruments used in this study were self-report questionnaires. Additional information was gathered using other standard physical outcome measures but was not included in this particular study. Psychological status of individuals has been assessed using self-report measures since Woodworth (1918) developed the Personal Data Sheet before the First World War. By developing such a scale, Woodworth not only provided a way by which the individual could “interview himself,” but he also “created a historical benchmark for a new modality of psychological measurement” (Derogatis & Melisaratos, 1983, pg. 595).

There are both advantages and disadvantages to the self-report method of assessment. Of particular advantage is the fact that, as a *self-report*, this type of measure does not require professional time and thereby provides an economical approach to accessing information not readily available through other evaluative methods. Self-report measures have the unique feature of offering information that reflects the experience of the specific individual who is responding and can rather easily be integrated into institutional or follow-up care routines while being compatible with statistical methodologies of scoring and interpretation (Derogatis & Melisaratos, 1983). In addition, several studies of self-report inventories have indicated that such measures are sensitive to a widely diverse number of therapeutic interventions (Kellner, 1971; Lyerly & Abbott, 1964).

However, there are distinct disadvantages to the use of self-reporting and the tacit postulations made regarding the validity of such measures. The predominate assumption made regarding these measures is that the individual being assessed will have the capability of being and/or will be accurate in the symptomatology and behavior descriptions (Wilde, 1972). According to Derogatis & Melisaratos (1983), such presuppositions cannot always be supported. However, despite concerns regarding these deficiencies, currently one of the most widely used forms of clinical measurements remains the self-report method.

According to Nunnally (1978) in his study and reported overview of psychological measurements, “even though self-inventories definitely have their problems as approaches to the measurement of personality characteristics, attitudes, values and a variety of other non-cognitive traits, they represent by far the best approach available” (pg. 141).

Although a wide variety of variables believed to influence outcomes were analyzed in this study, it was not fully comprehensive. One of the most evident omissions was with regard to premorbid psychological concerns. Historical research has confirmed the prevalence of premorbid psychological problems among the burn population (Fauerbach et al., 1999; Fauerbach et al., 2000). The presence of such dysfunction tends to not only place these individuals at greater risk for burn injury, but also hinder the recovery process. However, while the current study did not deliberately exclude individuals with premorbid psychological concerns, it did not quantify this variable in a way that allowed its influence to be analyzed either independently or in relation to other outcome variables.

Future Research

Further research into the adjustment problems of more specific subgroups would be of immense value to the burn population and to the individuals who seek to assist these trauma survivors. Also, the development of a strategy to not only limit the attrition rate but also increase the sample size of a study would greatly improve the ability to generalize study outcomes. Whether it be through internet outreach or multi-center affiliations, such an increase would substantially improve the validity of overall study findings. Additional funding that allows a monetary incentive for study participants to stay in the research project may generate larger sample sizes and help reduce attrition rates.

The present study supported several theories postulated in various studies regarding pain perception and recovery, and further studies might examine this relationship in greater detail. McNulty (2002) stated that coping modalities are influenced by pain perception and likewise, the individual's method of coping influenced how the pain was perceived. For example, if pain was perceived as uncontrollable or unbearable, then coping abilities tended to degenerate, yielding more maladaptive responses such as catastrophizing or aggression. Ptacek et al. (1995) suggested that acute procedural pain immediately postburn may directly impact later adaptation outcomes. Future studies may focus on pain and pain response style as a predictor of short- and long-term psychosocial adjustment.

The role that the individual's living situation may possibly play on recovery outcomes is another important factor that could be examined. Roughly 80% of the sample in this study were living with either a spouse, significant other or family member, and further research could yield valuable information regarding the importance of this factor in overall recovery outcomes. Also, other variables such as ethnicity or whether the individuals were employed or unemployed at the time of the burn injury could be analyzed as predictors of outcome.

As there were other standard physical outcome measures used to gather data in face-to-face interviews by the treating therapist which were not included in this particular study, the inclusion of such information would no doubt be informative. Most of the measures used in this study were subjective, i.e., self-reported by the participants from their own perspective. Objective measures may strengthen future studies. It might be assumed that integrating both subjective and objective data in future studies might provide a more comprehensive representation of actual outcomes.

Studies that focus on exceptional cases – those individuals who do not fit the expected pattern of recovery – may also contribute to an understanding of the variables

involved and what treatment should occur. As stated by Blumenfield & Schoeps (1992, pg. 605), the consummate goal for individuals who have survived burn injuries is to “become not ‘victims,’ but members of society with full participation. Each reintegrated burn survivor spreads the word that there is not only life after trauma, but meaningful, productive life.” Research that focuses on the individuals who are not able to meet this standard, and the variables impacting their status, may lead to improved treatment strategies.

Conclusion

This study concluded that the first two months after discharge appear to be a milestone in pain reduction and an improved ability to perform specific functional tasks. From 12 to 24 months postburn seems to be a milestone for more global areas of functioning such as an improvement in burn injury adaptation and re-integration into prior activities. Also, it was concluded that a relationship exists between increased emotional distress and both lower functional ability for up to 12 months as well as problems with community re-integration for up to 36 months postburn.

APPENDIX A
Description of Burn Injury Severity

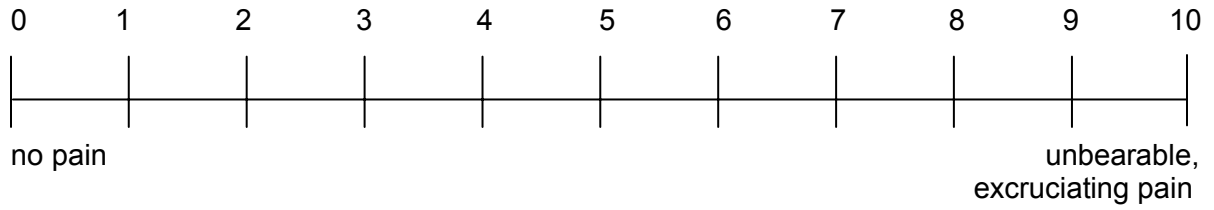
	First Degree Superficial	Second Degree Partial Thickness	Third Degree Full Thickness	Fourth Degree Full Thickness +
Skin depth	Epidermis	Epidermis-complete Dermis-partial	Epidermis-complete Dermis-complete	Epidermis-complete Dermis-complete Affects fat, bone, fascia, muscle
Mechanism of Injury	Sunburn (ultraviolet light); flash flame	Hot liquids or solids; direct flame; chemicals; clothing flame; ultraviolet light	Hot liquid or solids; flame; chemicals; electrical injury	Hot liquids/solids; flame; chemicals; electrical injury
Color	Erythematous; no blisters	Superficial burns are moist and blister. Deeper burns are white and dry	White, charred, brownish and leathery surface; eschar; charred vessels, dry	Same as 3 rd degree; also affects fat, bone, fascia and muscle
Pain	Painful; pain usually resolves within 3–5 days	Very painful	Limited/no pain.	Limited/no pain
Healing Time	5-10 days with no residual scarring	If superficial: 5-21 days, no grafting Deep: grafting may be required if converts to deep 2 nd degree	Grafting required	Reconstructive surgery usually indicated
Long Term Impact	May discolor		Usually have permanent impairments	Severe disfigurement

APPENDIX B
Brief Symptom Inventory (BSI)

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Nervousness or shakiness inside
2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Faintness or dizziness
3	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	The idea that someone else can control you thoughts
4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling others are to blame for most of your troubles
5	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Trouble remembering things
6	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling easily annoyed or irritated
7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Pains in heart of chest
8	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling afraid in open spaces or on the streets
9	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Thoughts of ending your life
10	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling that most people cannot be trusted
11	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Poor appetite
12	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Suddenly scared for no reason
13	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Temper outbursts that you could not control
14	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling lonely even when you are with people
15	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling blocked in getting things done
16	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling lonely
17	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling blue
18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling no interest in things
19	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling fearful
20	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Your feelings are easily hurt
21	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling that people are unfriendly or dislike you
22	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling inferior to others
23	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Nausea or upset stomach
24	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling that you are watched or talked about by others
25	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Trouble falling asleep
26	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Having to check and double-check what you do
27	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Difficulty making decisions
28	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling afraid to travel on buses, subways or trains
29	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Trouble getting your breath
30	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Hot or cold spells
31	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Having to avoid certain things, places or activities because they frighten you
32	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Your mind going blank
33	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Numbness or tingling in parts of your body

34	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	The idea that you should be punished for your sins
35	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling hopeless about the future
36	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Trouble concentrating
37	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling weak in parts of your body
38	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling tense or keyed up
39	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Thoughts of death or dying
40	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Having urges to beat, injure or harm someone
41	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Having urges to break or smash things
42	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling very self-conscious with others
43	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling uneasy in crowds, such as shopping or at a movie
44	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Never feeling close to another person
45	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Spells of terror or panic
46	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Getting into frequent arguments
47	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling nervous when you are left alone
48	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Others not giving you proper credit for your achievements
49	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling so restless you couldn't sit still
50	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feelings of worthlessness
51	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feeling that people will take advantage of you if you let them
52	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Feelings of guilt
53	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	The idea that something is wrong with your mind

APPENDIX C
Pain Analog Scale (PAS)



- _____ 1. Rate your current pain.
- _____ 2. Rate your worst pain in the last 24 hours.
- _____ 3. Rate the least pain you've experienced in the last 24 hours.

APPENDIX D
Functional Assessment Screening Questionnaire (FASQ)

1. _____ Getting up from a low seat like a sofa
2. _____ Climbing a flight of stairs
3. _____ Shopping for groceries or other goods
4. _____ Sitting a long time, like for 30 minutes
5. _____ Standing for a long time, like for 30 minutes
6. _____ Reaching and grasping something off a shelf
7. _____ Kneeling or bending down to the floor
8. _____ Driving an automobile

_____ FASQ Total Score

APPENDIX E
Burn Specific Health Scale (BSHS)

Below is a list of problems, complaints and feelings that people sometimes have. Read each one carefully and select one of the numbered responses that best describes how you feel. Select your answer carefully from the scale below. Do not skip any items. If you have any questions or difficulties with any of the items, please ask for help.

0 = Extreme
1 = Quite a bit
2 = Moderate
3 = A little bit
4 = Not at all

Questions 1-20: Using the scale above (0-4), how much difficulty do you have?

- _____ 1. Bathing independently
- _____ 2. Going to the toilet by yourself
- _____ 3. Dressing by yourself
- _____ 4. Feeding yourself
- _____ 5. Getting in and out of bed
- _____ 6. Getting in and out of a chair
- _____ 7. Walking by yourself
- _____ 8. Using stairs
- _____ 9. Getting around independently (including driving or getting rides)
- _____ 10. Doing your own shopping
- _____ 11. Signing your name
- _____ 12. Eating with utensils
- _____ 13. Tying shoelaces, bows, etc.
- _____ 14. Picking up coins from a flat surface
- _____ 15. Turning a door knob
- _____ 16. Doing your regular chores around the house
- _____ 17. Carrying on ordinary leisure activities
- _____ 18. Participating in physically active pastimes (e.g. tennis, bowling, golf, basketball)
- _____ 19. Working in my old job performing my old duties
- _____ 20. Taking care of my skin

- 0 = Extreme
- 1 = Quite a bit
- 2 = Moderate
- 3 = A little bit
- 4 = Not at all

Questions 21-50: Using the scale above (0-4), how much difficulty do you have?

- _____ 21. Changes in my appearance have interfered with my relationships.
- _____ 22. Sometimes, I would like to forget that my appearance has changed.
- _____ 23. I feel members of my family are uncomfortable around me.
- _____ 24. I feel that my burn is unattractive to others.
- _____ 25. People act as if there was something wrong with me.
- _____ 26. I don't think people would want to touch me
- _____ 27. I am uncomfortable around other people.
- _____ 28. I suffer from nightmares.
- _____ 29. I have feelings that something terrible is about to happen.
- _____ 30. I feel uncomfortable around other people.
- _____ 31. I sometimes feel afraid for no reason at all.
- _____ 32. I'm upset because I can't do some things I used to be able to before the injury.
- _____ 33. I no longer feel like doing things.
- _____ 34. I am troubled by feelings of loneliness.
- _____ 35. I have feelings of ending my life.
- _____ 36. My feelings are easily hurt.
- _____ 37. I often feel sad or blue.
- _____ 38. I feel discouraged about the future.
- _____ 39. I have temper outbursts that I can't control.
- _____ 40. I am easily annoyed or irritated.
- _____ 41. Sometimes, I feel like smashing things.
- _____ 42. I am not in control of things.
- _____ 43. I really have to push myself to do things.
- _____ 44. I don't take good care of myself.
- _____ 45. I seem to have more accidents than most people.
- _____ 46. At times, I think I have had an emotional problem.
- _____ 47. I blame myself for things.
- _____ 48. I feel tired, worn out, used up.
- _____ 49. I don't think I could handle any serious problems in my life.
- _____ 50. I am troubled by recurrent unpleasant thoughts.

- 0 = Extreme
- 1 = Quite a bit
- 2 = Moderate
- 3 = A little bit
- 4 = Not at all

Questions 51-80: Using the scale above (0-4), how much difficulty do you have?

- _____ 51. I am not interested in doing things with my friends.
- _____ 52. I am no longer comfortable with my friends.
- _____ 53. I don't enjoy visiting people.
- _____ 54. Some of my old friends have dropped out of sight.
- _____ 55. My injury has put me further away from my family.
- _____ 56. I wish I had more family responsibility.
- _____ 57. I wish I could do more with my family than I am doing.
- _____ 58. I would rather be alone than with my family.
- _____ 59. I don't like the way my family acts around me.
- _____ 60. My family would be better off without me.
- _____ 61. I have no one to talk to about my problems.
- _____ 62. I don't have any hobbies or pastimes.
- _____ 63. I feel frustrated because I cannot be sexually aroused as well as I used to.
- _____ 64. I am simply not interested in sex any more.
- _____ 65. I no longer hug, hold or kiss.
- _____ 66. Typically, I don't follow doctors' instructions.
- _____ 67. I keep worrying about my health.
- _____ 68. My burn has open areas or keeps breaking down.
- _____ 69. I have a lot of itching.
- _____ 70. I have a lot of pain.
- _____ 71. My physical activities are very limited.
- _____ 72. I have lost my strength.
- _____ 73. I don't have any energy.
- _____ 74. My general appearance really bothers me.
- _____ 75. I am bothered by the way people react to me.
- _____ 76. I have thoughts or images of my accident.
- _____ 77. I need a lot of help from others.
- _____ 78. I really feel other people are better than I am.
- _____ 79. I have feelings of nervousness and shakiness.
- _____ 80. I have feelings of being trapped or caught.

81. WHAT IS YOUR JOB SITUATION NOW?

CHECK ONE BOX ONLY

- a. Better job than before
- b. In old job doing same work as before
- c. In old job doing different work or less time at work
- d. Part-time odd jobs for pay
- e. Compensation or suit or hearing pending
- f. Have had a settlement for injury
- g. Out of work with state, rehabilitation, or insurance aid financially
- h. Out of work with no compensation, or retired
- i. Other – please specify

APPENDIX F
Community Integration Questionnaire

Please check the best answer for each question.

1. Who usually does shopping for groceries or other necessities in your household?

- yourself alone
- yourself and someone else
- someone else

2. Who usually prepares meals in your household?

- yourself alone
- yourself and someone else
- someone else

3. In your home, who usually does normal everyday housework?

- yourself alone
- yourself and someone else
- someone else

4. Who usually cares for the children in your home?

- yourself alone
- yourself and someone else
- someone else

5. Who usually plans social arrangements such as get-togethers with family and friends?

- yourself alone
- yourself and someone else
- someone else

6. Who usually looks after your personal finances, such as banking or paying bills?

- yourself alone
- yourself and someone else
- someone else

Can you tell me approximately how many times a month you now usually participate in the following activities outside your home?

7. Shopping

- never 1-4 times 5 or more

8. Leisure activities such as movies, sports, restaurants...

- never 1-4 times 5 or more

9. Visiting friends or relatives

_____ never _____ 1-4 times _____ 5 or more

10. When you participate in leisure activities do you usually do this alone or with others?

_____ mostly alone
_____ mostly with friends who have burn injuries
_____ mostly with family members
_____ mostly with friends who do not have burn injuries
_____ mostly with a combination of family and friends

11. Do you have a best friend with whom you confide?

_____ yes _____ no

12. How often do you travel outside the home?

_____ almost every day
_____ almost every week
_____ seldom/never (less than once per week)

13. Please choose the answer below that best corresponds to your current (during the past month) work situation:

_____ full-time (more than _____ 20 hours per week)
_____ part-time (less than or equal to _____ 20 hours per week)
_____ not working, but actively looking for work
_____ not working, not looking for work
_____ not working, retired due to age

14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:

_____ full-time
_____ part-time
_____ not attending school or training program

15. In the past month, how often did you engage in volunteer activities?

_____ never
_____ 1-4 times
_____ 5 or more

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VITAE

Sheila Ainsworth Grace, the daughter of Frances Edmondson Ainsworth and the late Lloyd H. Ainsworth, was born August 16, 1950 in Ft. Stockton, Texas. She lived in Iraan, Texas until 1966 when she finished her sophomore year at Iraan High School and married. A non-traditional student, she returned to school after 31 years, enrolling in Eastfield Community College in Mesquite, Texas in May of 1996. While at Eastfield, she served as president of the Student Senate for two years, was a LeCroy Scholar and was selected as Eastfield's Student Leader of the Year in 1998. She was also a member of both the Alpha Delta Omega and Phi Theta Kappa honor societies and in 1999 was selected to the All-USA Academic First Place Team. After completing associate degrees in both Social Work and Substance Abuse Counseling, she entered The University of Texas Southwestern Medical Center's Allied Health Rehabilitation Counseling Program in September of 2000. While at U.T. Southwestern, she served as president of Student Affairs in 2000 and consequently served as the student representative to the Alumni Board of Trustees. She received the degree of Bachelor of Science from U.T. Southwestern Medical Center in May of 2001, graduating with honors. During her years at U.T. Southwestern she was employed as a recruiter for the university from 2000 to 2004. In September, 2001, she entered the Graduate School of Biomedical Sciences at the University of Texas Southwestern Medical Center. She was awarded the degree of Master of Science in Rehabilitation Counseling Psychology in May, 2006. In 2003, she married James Michael Grace of Fredericksburg, Texas. She has three children: James Clayton Donowho, born in 1968, a daughter, Brandy LaNell Baron Mills, born in 1977 and a son-in-law, Ronald Ray Mills. She also has four grandchildren, Tory & Rion Mills and Taylor & Jim Donowho who range in age from five years to nine years of age and who are the light of her life. Another grandchild is expected in November of 2006.

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