A QUALITATIVE EXPLORATION OF THE EXPERIENCES OF ADULT THERMAL BURN SURVIVORS: THE NAVIGATION TOWARD SURVIVAL, RECOVERY, AND HEALTH

by

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ABSTRACT

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Burn injury is more common in our society than one might think, impacting the lives of over 1.1 million people within the United States annually (Centers for Disease Control & Prevention, 2011). Taking into account current advancements in burn trauma care, approximately 95 percent of those hospitalized will survive their injuries. With increased survival rates, greater attention is being focused on the psycho-social aspect of burn treatment and rehabilitation. There is an opportunity for health educators to affect the wellness outcomes of adult burn trauma survivors and to support their growth beyond survival status. This may not constitute recovery to their pre-injury lives, but rather recovery to lives closer to optimal health/wellness as opposed to mere acceptance of their current situation. Utilizing a phenomenological qualitative design, the purpose of this study is to explore the burn related experiences and underlying dimensions of resilience among burn survivors living in the Midwestern United States. The theoretical dimensions of resilience framework have been successfully utilized as a foundation for interventions with other at-risk populations affected by compromised health status and may be useful with adult burn trauma patients to enhance recovery outcomes as well as those who are living in the community. The outcome of this study may increase the opportunity for health educators to understand the experience of burn trauma and the impact of resilience on positive recovery outcomes.
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PREFACE

A PERSONAL REFLECTION

Burn injuries and the people who’ve survived them have held a very special place in my heart since I first became aware that I was not the only one with the scars that signify this type of traumatic experience. The “accident” occurred when I was six years old. We were waiting to go swimming in our backyard pool after lunch, playing with matches with my older brother and sister while my mother attended to some unknown task with my eldest sister. We planned to melt crayons and as the youngest in the family, I was the one charged with quietly sneaking into the house and securing the crayon while my eleven year-old brother built a small fire with twigs and leaves in the barbeque grill. We had been warned by parents and teachers never to play with matches and that was why it was so important not to raise our mother’s suspicions as to our activities. At least that was what my brother impressed upon me at the time.

I stood patiently waiting in front of the rusty open-faced charcoal grill that stood at the back corner of our house as instructed. I had that green crayon clutched in my hand as my brother emerged from the garage that stood no more than thirty feet away. The last thing I fully remember was watching him come through the small side door of our garage with a shiny tin can in his hand. I remember my nine-year old sister telling him no, but even that image is fuzzy, as if in a dream and hardly seems real. After that point, there are only sporadic glimpses of events which play like a flicker film in my mind, such as raising my right hand to see the now charcoal grey skin lift and float away like the layers in a stack of newsprint burning slowly in a breeze, not recognizing the thing at the end of my arm as belonging to me. I remember seeing the faces of my siblings who stood in the driveway looking back at me, horrified, and I remember
knowing something was terribly wrong. Most of all I remember the screaming, but I don’t know if I was the one who was actually making all of the noise that resounded in my ears.

The story that emerged later is that the fumes had collected around me from the small can of gasoline my brother brought from the garage and then ignited when he threw the liquid contents into the fire he had built in the grill. The fireball hit me in the face, and the fumes that had clung to my skin on that hot and humid July day set me ablaze. I did not stop, drop, and roll; I ran, and my mother and brother had to catch me to smother the flames with a beach towel that hung from the clothes line in our back yard. I remember my father coming home after my mother called him at work, the ride to the doctor’s office in the small farming community in which my family lived and where my father owned a dry goods store, then the ride in my father’s car to the hospital that was more than 30 miles away. I remember the group of people who were standing outside waiting for us as we drove up to the emergency room door. They leaned into the car with smiling eyes looking over stark white surgical masks as they gently lifted me from the backseat. There wasn’t any pain at that point, (which, I was told later, was due to the damage from the injury that had burned past my nerve endings) but rather an incredible and profound thirst that no one seemed to be concerned about but me. I vividly remember asking for water until a kind voice from behind one of the white cotton masks promised to get me some water soon. I recall the flurry of activity as they brought me inside the E.R. and the people dressed in green scrubs whose words were so reassuring, telling me they would take care of me. And oddly, I remember feeling very secure in their care as I drifted off into unconsciousness.

I can’t recall much about what occurred over the following two months. The details have been filled in by my parents and those from the neighborhood that provided social support to my family and me. According to family legend, the doctor told my parents to go home, that it
was unlikely I would live through the night. I had sustained first, second, and deep third degree burns over 35 percent of my body. In 1964 there were very few designated burn units in the United States and certainly not one in the small city hospital in Southwestern Michigan my father had driven me to, as instructed by our family physician. My parents returned to the hospital the following day and stood watch over my hospital room which they were not allowed to enter. The young plastic surgeon who had taken me into his care had set up a sterile environment within my room, blocking the windows and mirrors with sterile towels. No one could enter except medical staff who bustled in and out, draped in long, sterile gowns, all in an effort to decrease the risk of infection. My parents would alternate that daily vigil, with my father arriving to stand watch from 6 a.m. until 8 a.m. when my mother arrived, and then driving the thirty plus miles back to our hometown for a day’s work. My mother would stay until my father returned at 6 p.m. after closing his business for the night, then driving the distance back home to attend to the rest of our family. My father would stay for the evening, returning home only after he knew I was asleep for the night. I spent three and a half months in that hospital room before being discharged to return to my home, family, and the rural community in which my family had lived for two generations. My siblings had been farmed out to extended family members and neighbors while my parents struggled to figure out the logistics and resources needed to contend with this family crisis. The only image of my pre-injury self that was evident to the people inside and outside of the hospital room was the small two by three inch photograph that was tacked to the door; my kindergarten picture taken that school year which now still holds a place of honor in one of my scrapbooks.

I grew up with the kind of disfigurement that typically accompanies second and third-degree thermal burns to the face, back, and limbs. The marks left behind that others see began as
red, twisted scars that grew in ropes across my damaged skin. But, after countless reconstructive surgeries and time, the scars have softened, losing a good deal of the color that drew the most stares from others. Most burn survivors I’ve met in my involvement with the burn community have routinely told me how great my scars look and how they can hardly be seen despite my own feelings of how obvious they seem. I often feel awkward when receiving these compliments, not believing they are warranted or feeling guilty that somehow I was luckier than the person giving the compliment. The most significant commonality I share with participants in this study is that the deepest scars are not visible, but lay within the depths of the emotional and psychological self. For me, burn injury has impacted not only how I see myself, but how I imagine others see me.

More than twenty years passed before I met another person who had sustained a major burn injury. I had accompanied my eldest sister to a doctor’s appointment in the hospital where I’d been treated as a child. I stood in the large lobby of Bronson hospital with my sister’s and my children, looking at the directory for names of doctors who had treated me so many years earlier. The current director of the large burn unit that now serves Southwestern Michigan had the same name as the resident who had been included in my care as a child. I rode the elevator up to the floor where the burn unit was located and rang the doorbell on the wall next to the closed doors that protected burned patients. A nurse answered the door and I explained my connection to the hospital and the length of time since I had been treated. She informed me of the history of the burn unit and when the doctor whose name I recognized founded it. She invited me to tour the unit however I had four young children in tow and felt it inappropriate to include them in the tour, so she invited me to join their support group for burn survivors. The invitation was thrilling in a sense, I had never considered there could be such a group that was
focused on improving the lives of burned people, however I had to decline. After returning home to Wisconsin following our brief visit to Michigan, I began to investigate whether there was such a group in the city in which I lived. I found a group and was introduced to the local burn community through a support group affiliated with St. Mary’s burn center in Milwaukee, Wisconsin in 1988. It was at that meeting I first became aware of the term burn “survivor” as opposed to burn “victim,” a moniker that encompasses not only survival, but a kind of rekindled spirit that supports new life and beauty post-injury (Phoenix Society for Burn Survivors, Inc. brochure, 1988).

Over the course of the following years, I became very involved with the Phoenix Society for Burn Survivors, an international organization that provides peer support for burn survivors and their families. I invested my time in attending and speaking at conferences, organizing and running an active burn support group after moving to Rochester, New York, and participating in the national burn support network. It was through the Phoenix Society that I first became acquainted with a past director of the support group in Missouri who invited me to speak at a conference the group sponsored in 1997. Since that time, I’ve fallen away from the burn community in practice, but never stopped trying to understand why some people who are severely burned thrive and go on to lead productive lives, while others with less severe injuries cannot regain important dimensions of health. I returned to the burn community to explore the experiences of adults who have sustained traumatic burn injury, to discover how they believe they were able to navigate their survival, recover, and health following traumatic burn injuries.

Since I began this journey toward a doctorate in Health Education three years ago, I have often been given quizzical looks when asked about my research interests. It was difficult for me to articulate what I believed to be true about survivors of major burn injury and how they pick
themselves up and go on to lead productive lives in spite of their personal burn-specific hardships. Over the years of working with burn survivors, I had come to observe the same kind of resilience in other burn survivors as I felt within myself. There seemed to be a commonality within this apparent resilience that carries survivors through the acute phase of burn treatment, then supports them through healing, and continues to guide them toward burn-specific health/wellness and adjustment as they regain their position within their social world.

My interest in bettering the lives of burn survivors continues to motivate me. However, there is a difference between what I understood about burn rehabilitation and health since my introduction to burn support, as I’ve come to understand the importance not only of the physical condition, but the additional social, emotional, spiritual, environmental (Greenberg, 1985), and vocational (Eberst, 1984) dimensions that are necessary for holistic health and wellness. Through instruction and mentoring, I was taught by my professors about the functions of public health and health education and how the professions provide a platform for supportive health-related attention and educational programming, as well as theories that might explain the phenomenon of survival and positive holistic health and wellness following such a trauma. For me, the instruction within this Health Education program set me free by providing the words to articulate the thoughts that have been formulating for a lifetime. Through the results of this study, I hope to identify some of the important personal factors that support survival, recovery, and burn-specific health/wellness. I hope the results of this study will be beneficial to health-related providers, and ultimately provide the kind of supportive programming to the burn community that could inspire and promote the resilience that lies within each of us.
CHAPTER ONE

INTRODUCTION

“When you talk about recovery, it is being able to call this thing that happens to us, be able to get it in the background where you can be in the foreground...and your life means something...that’s it”
Historically, burn care researchers have explored physical, vocational, and psychological barriers to burn-specific health and quality of life for adult burn survivors through traditional quantitative methodologies. There have been far fewer studies exploring and interpreting burn patient/survivor strengths as described through qualitative measures that capture survivors’ personal stories about the burn event and the journey toward recovery. This study offers an opportunity to explore the phenomenon of burn injury and its experiential impact on adults between the ages of 24 and 65 and their significant others living in the Midwestern United States, and how they organize meaning and reconstruct their life stories relative to their survival, recovery, and health/wellness. By increasing theoretical knowledge relative to the innate psychological, emotional, spiritual, environmental, social, and vocational capacities of burn survivors, we may ultimately benefit by utilizing that theoretical framework within future interventions designed to improve long-term health/wellness outcomes for survivors of major burn injuries.

Background of the Problem

Burn injury is more common in our society than one might think, affecting approximately 1 percent of the population each year (Muller, Pegg, & Rule, 2001), accounting for more than 1.25 million people being burned in the United States (Centers for Disease Control and Prevention, 2011). Twenty years ago burn injuries that required hospitalization accounted for more than 100,000 patients (Muller, Pegg, & Rule, 2001) and an estimated two million yearly hospital bed days (Currerie, Luterman, Braun, & Shires, 1980). With advancing medical and transport capabilities, mortality rates from “massive” traumatic burn injury have decreased from
5.3 percent to 3.4 percent, indicating a substantial downward trend (Moi, Vindenes, & Gjengedal, 2008; Muller, Pegg, & Rule, 2001). However, these domestic statistics do not reflect the incidence of burn injuries associated with increasing numbers of wounded warriors returning from combat zones. Current wartime casualties from incendiary weapons produce devastating injuries, including major thermal burns to the hands and face (Cancio, et al., 2005; Hoge, Castro, Messer, McGurk, Cotting, & Koffman, 2004; Mora, Ritenour, Wade, Holcomb, Blackbourne, & Gaylord, 2009).

The Centers for Disease Control and Prevention (CDC) (2006) indicate that every thirty minutes someone is injured by fire in the United States. Burn injury to the body may result when the body comes in contact with various destructive sources including heat, fire, chemicals, and electricity. Physiologically, the skin is considered the largest organ, responsible for insulating the body by controlling heat, maintaining critical fluid balance, and acts as the body’s primary line of defense against infection (Al-Mousawi, Mecott-Rivera, & Herndon, 2009). There are four internationally recognized levels utilized by burn care providers to reflect their estimation of burned patients’ tissue damage and depth of injuries (Atiyeh, Gunn, & Hayek, 2005). These levels include: 1) superficial epidermal first-degree burns; 2) superficial partial-thickness second-degree dermal burns; 3) deep partial-thickness second degree dermal burns; 4) full-thickness sub-dermal third-degree burns (Atiyeh, Gunn, & Hayek, 2005). “Severely burned patients not only lose this protection to a major extent, becoming particularly susceptible to infection, but also lose a great amount of heat, plasma, and liquids that if left uncorrected, will cause hypothermia, hypovolemic shock, and renal insufficiency” (Al-Mousawi, Mecott-Rivera, & Herndon, 2009, p. 552). Of those patients that are burn injured, one of them will die from their injuries every 135 minutes (CDC Fact Sheet, 2011), leaving approximately 95 percent of
those hospitalized with traumatic burns to survive and with the assumption they will adapt to their injuries (Ullrich, Askay, & Patterson, 2009).

In spite of the tremendous efforts of those practicing in the public health and health education arenas to prevent burn injury through fire prevention campaigns and educational programming, burn injuries continue to present a significant social and fiscal burden through patient mortality, morbidity, and potential for long-term disability (Brusselaers, Hoste, Montrey, Colpaert, De Waele, Vandewoude, & Blot, 2005). Yet, little is known about how young and middle aged adults living in the United States who are able to achieve positive health outcomes after major burn injury adapt to the burn-related challenges within their realities. There is also the prospect that there is a more encompassing theoretical framework that might explain how they navigate their journey toward recovery from burn trauma, and ultimately, health/wellness.

Statement of the Problem

The term “recovery” is sometimes used to indicate patient progress after admission and discharge from a burn unit. From a clinical perspective, recovery is divided into three phases: acute, healing, and rehabilitation (Summer, Puntillo, Miaskowski, Green, & Levine, 2007). The acute phase represents the initial critical period following admission as the patient clings to life, instinctively calling on whatever internal forces she/he may possess to survive following burn injury, typically lasting a few days to several weeks. The intensive-care treatment patients experience during this acute phase may include fluid resuscitation to replace vital fluids lost through burn wounds, intubation to facilitate breathing, and painful procedures to excise (clean/debride) wounds. Obstacles to survival may include systemic complications such as liver and kidney dysfunction (Jeschke, 2009), edema (swelling), pneumonia, and sepsis (infection) (Baxter, 1978). Once survival of the patient is established, goals for patient care shift. “During
the healing stage, the goal is to promote healing, either by removing devitalized tissue from the injured area, using topical enzymatic preparations and frequent dressing changes or by surgical excision and grafting” (Summer, et al., 2007, p. 537). The third and final phase is rehabilitation which typically entails completion of wound closure, scar maturation, and physical and occupational therapy to prevent contractures and improve range of motion to affected areas (Summer, et al., 2007). Depending on the extent of burn injuries, the rehabilitative phase may extend years after the patient is discharged from the burn unit.

Psychosocial features of burn injuries are less predictable than physical features. Following a major burn trauma, patients admitted to a burn unit are found to exhibit a “rare cocktail” of psychological reactions: shock, anxiety, confusion, grief, depression, denial, fear, euphoria about surviving, delirium, accompanied by a sense of loss of independence and self-image (Partridge & Robinson, 1995, p. 643). As I began to look at burn survivors and the burn community through the lens of researcher as opposed to participant, I’ve come to understand that what constitutes positive recovery outcomes and health for burned patients and how they meet those challenges not only lies in the minds of medical providers and theorists, but is also greatly dependent on how burned individuals make meaning for their burn-related experiences. Within this context, a useful definition for “meaning” can be thought of as a mental representation of possible associations among events, relationships, and cognitions following a significant event (Park, 2010). Burn survivors must find ways to reconstruct their life stories by making meaning for the burn event, their burn injuries, their burn-related experiences, and the changes brought about by their physical, emotional, and psychological recovery needs. “Thus, meaning connects things” (Park, 2010, p. 257).
Consequences associated with major burn injuries pose a threat to the biological, emotional, psychological, spiritual, environmental, and social stability of the burned person. The burn event affects a significant turning point for the patient, his/her family, and the communities in which they live and work. Scars from partial and full thickness burns are typically disfiguring, and require multiple reconstructive surgeries over a number of years. Despite surgical reconstruction of burned areas, the burned person will never look the same as before the burn event. They have no choice but to acknowledge the reality of their injuries and adapt to changes in the way their body is functioning. However, adaptation to changes in physical appearance and responses from others may be more challenging (Van Loey & Van Son, 2003), and more difficult to assess. Stress reactions associated with the cause and circumstances surrounding burn injuries are only a portion of psychosocial challenges for the burned person. The traumatic nature of the burn event and the incredibly painful burn care treatments often lead to symptoms of post-traumatic stress (PTSD), and other mental health disturbances (Van Loey & Van Son, 2003). While many burn survivors adapt well with no significant change in reported quality of life, there are a significant number of burned people who do not rebound (Van Loey, Faber, & Taal, 2001). Major burn injuries leave the person subject to a pressing need to cope with the multidimensional health consequences of their burn injuries (Van Loey, Faber, & Taal, 2001). Within patient-centered healthcare, the goal of treatment is to produce the most effective health outcomes based upon the integration of conventional ideologies of disease in concert with patients’ unique experiences of illness (Chenail, 2011). With the negative shift in mortality rates associated with severe burn trauma in the last quarter century and more people surviving often devastating burn injuries, greater investigative attention is being focused on psychosocial aspects of burn treatment (Diefede, Cukor, Lee, & Yurt, 2009; Van Loey & Van Son, 2003), challenges
to long-term psychosocial adjustment (Williams, Doctor, Patterson, & Gibran, 2003), and quality of life (Moi & Gjengedal, 2008). “Reducing the mortality rate intensifies the importance of the question of what quality of life the survivor may anticipate. The question immediately following is what factors may enhance or impede positive psychosocial adjustment” (Blakeney, Herndon, Desai, Beard, Wales-Seals, 1988, p. 661).

Factors that positively impact burn adjustment may then be thought of as protective factors as identified within the resilience framework. Quality of life is difficult to assess as it is a subjective construct. In an effort to quantify quality of life, burn care researchers have identified return to work (RTW) as a representation of the patients’ adaptation and return to previous/acceptable levels of social and vocational reintegration (Dyster-Aas, Kildal, Willebrand, Gerdden, & Ekselius, 2004). Social stigma as to the survivors’ deviant appearance (Moi & Gjengedal, 2008), guilt and blame associated with how the burn event occurred (Kiecolt-Glaser & Williams, 1987; Patterson, Everett, Bombardier, Questad, Lee, & Marvin, 1993), and vocational challenges due to loss of function and “perceived” disability (Gammon & Abrams, 1993) continue to be a concern long after the patients’ burns have “healed.”

Within the individual journey toward recovery, patients’ long-term health outcomes also may be difficult to assess due to individual physical, mental, and emotional health recovery paths and unique social consequences of thermal burn injuries (Falder, Browne, Edgar, Staples, Fong, Rea, & Wood, 2009). Many patients discharged from burn units are able to adapt to the consequences associated with their burn injuries, making the transition from burn “victims” to burn “survivors” over time. Positive burn-specific adaptation supports reintegration into survivors’ social and vocational worlds, and serves to foster holistic health/wellness, and potentially improved quality of life. Return to work (RTW) is considered an important aspect of
the recovery process for adults, implying burn-specific adaptation (Oster, Kildal, & Ekselius, 2010).

“There are personal, social, and economic reasons for why RTW is one of the most important outcome measures of health care. Working capacity is an important factor in quality of life of burn patients and can be seen as a representation of normality and social integration” (Oster, Kildal, & Ekselius, 2010, p. 540).

However, very little is known about how early and middle adults living in the United States navigate their journey toward survival, recovery, and health, how they make meaning for their burn-related experiences within their life stories, and how they conceptualize their individual health/wellness in relationship to quality of life.

A body of quantitative literature has been amassed over the last several decades reflecting aspects of adult burn treatment (Atiyeh, Gunn, & Hayek, 2005; Brigham, & McLaughlin, 1996; Falder, et al., 2009; Munster, 1980), perceived health (Wikehult, 2008), coping patterns and strategies (Kildal, Willebrand, Andersson, Gerdin, & Ekselius, 2005; Willebrand, Andersson, Kildal, & Ekselius, 2002), adjustment (Bernstein, O’Connell, & Chedekel, 1992; Kleve & Robinson, 1999; Wallace & Lees, 1988), adaptation (Dyster-Aas, Kildal, Willebrand, Gerdin, & Ekselius, 2004), psychological health (Blakeney, Herndon, Desai, Beard, Wales-Seale, 1988; Franulic, Gonzales, Trucco, & Vallejos, 1996), quality of life (Leblebici, Adam, Bagis, Tarim, Noyan, Akman, Havelar, 2006; Moi & Gjengedal, 2008) and burn-specific health (Van Loey, Faber, & Taal, 2001; Willebrand, Andersson, Kildal, Gerdin, & Ekselius, 2006) of burn survivors. “These quantitative methods are often less suited to exploring personal, social, cultural, spiritual, and other meanings and constructions in relation to the ‘burn identity’ (Lau & van Niekerk, 2011, p. 1166). Yet, there has been minimal qualitative inquiry into the unique
personal stories of how adult survivors perceive the lived experience of major burn injury (Moi & Gjengedal, 2008), specifically within the U.S. “...investigating how people respond when they are severely burned presents an opportunity to study an array of psychological phenomena, including acute pain control, reactions to hospitalization and medical procedures, post-traumatic stress disorder, and the influence of unusual life events on general adjustment” (Patterson, Everett, Bombardier, Questad, Lee, & Marvin, 1993, p. 362). Collecting and interpreting burn survivors’ personal stories for shared meaning through phenomenological, qualitative methodology will provide health educators and burn care providers with a deeper understanding of how burn injuries and recovery are experienced and understood by the survivors themselves (Moi, Vindenes, & Gjengedal, 2008). Through these shared stories, we may gain knowledge of how survivors’ develop meaning for their burn-related experiences within their life stories, and how they perceive the personal strengths that contributed to their survival, recovery, and health/wellness. From this perspective, we may learn more about what patients know, anticipate, and assume about their treatment, services, and aftercare, as well as their quality of life (Chenail, 2011) and health.

Need for the Study

I’ve spent the past eighteen years as a Licensed Clinical Social Worker, practicing in both health and mental health settings, but have dealt primarily with mental health issues affecting my clients. In pursuing a doctorate in health education, my thoughts have extended beyond the bounds of mental health to a holistic approach to health and wellness that encompasses more than the physical or mental self, but includes additional dimensions that are important for optimal health/wellness outcomes. Health/wellness is more than the absence of illness, but rather an integration of six dimensions of health: physical, social, mental, emotional,
environmental, and spiritual dimensions that support health and wellness (Greenberg, 1985). Productivity plays a vital part within an individual’s self-esteem and feelings of purpose, and also fulfills some cultural expectations for people. Eberst (1984) suggests that vocational health is necessary and should be included within these important health/wellness dimensions. After reviewing the literature and considering these important dimensions, I’m left with the continuing question; how do some adults who have sustained major burn injuries rebound, while others with similar or lesser injuries do not? And, if we are able to capture the essence of study participants’ personal resources that inspire and support positive adaptation and burn-specific health/wellness, can those strengths be promoted within other burned patients that might then inspire their innate strengths to support positive long-term burn-specific health outcomes? What protective factors or individual strengths support survivors as they navigate the arduous path toward recovery from major thermal burn injuries?

Due to the devastating consequences of major burn injuries, burn survivors are called upon to make huge adjustments within themselves and their environments. Over the years, I’ve had the opportunity to listen to many burn survivors’ stories of survival and rehabilitation. Their individual reflections identify personal strengths of physical, social, emotional, spiritual, environmental, and vocational reintegration, adaptation, growth, and resilience. These personal assets serve to assist the burned patient beyond the baseline of life or death, toward recovery and self-defined “survivor” status. There are few qualitative studies conducted with adult burn survivors that explore their burn-specific experiences (Bernstein, O’Connell, & Chedekel, 1992; Chedekel & Tolias, 2001; Cox, Call, Williams, & Reeves, 2004; Holaday & McPherson, 1997; Lau & van Nierkerk, 2011; Moi & Gjengedal, 2008; Moi, Vindenes, & Gjengedal, 2008; Morse & Mitcham, 1998; Morse & Carter, 1995; Williams, Davey, & Klock-Powell, 2003). Of those
qualitative investigations published, several are focused specifically on adolescent survivors’
psychosocial benefits of participation in burn survivor support groups (Chedekel & Tolias,
2001), how children and adolescent attendees at burn camp benefit from normalization of burn
scars and peer support (Cox, Call, Williams, & Reeves, 2004), and resilient factors that promote
adaptation following childhood burn injuries (Holaday & McPhearson, 1997).

One of the earliest qualitative studies focusing on adult burn injury was a piloted project
focusing on how personality features, affective expression, and the impact of social support on
long-term adjustment to burn injury (Bernstein, O’Connell, & Chedekel, 1992). Another
narrative qualitative study with adult participants searched for possible explanations of how
patients cope with burn injuries utilizing grounded theory. Morse & Mitcham, (1998) focused
their research how burn patients use “disembodiment” as a means for coping with “agonizing”
pain associated with not only their burn injuries, but burn treatments as well (p. 668).

Researchers have investigated how the unique passage of time is necessary for burn patients to
 evolve from the initial traumatic experience of “enduring” their burn-related pain to the cognitive
distance necessary for patients to reflect on the “suffering” they have experienced (Morse &
Carter, 1996, p. 43). They asserted that interpersonal losses associated with the traumatic burn
event, such as loss of loved ones, are also experienced as “enduring and suffering” (Morse &
focused on the limitations and growth potential involved within new bodily awareness as
survivors learn to live with their altered functional abilities and appearance (Moi, Vindenes, &
Gjengedal, 2008) and regaining freedom from feelings of dependence associated with burn
burn survivors’ personal stories through a biographical narrative approach and focused on burn
survivors’ resilient meaning-making and reconstruction of sense of self. “A small cluster of studies have shown, alongside emotional struggles of sadness, anger, fear, grief, and near suicidality, survivors of burns traumatic injury or illness were also able to reframe their adversity in the context of personal growth, meaning making, epiphinal experiences, insight, gratitude, forgiveness, and spiritual awakenings, striving to regain self, and striving for regained freedom” (Lau & van Niekerk, 2011, p. 1168).

Along the path toward emotional and physical recovery from any significant illness or injury, it is imperative that individuals learn to cope with new and stressful experiences, altering their cognitive and affective response to the changes. Positive coping skills require an understanding of or meaning for how their lives have been affected by the experiences, and/or how the experiences have affected their sense of self. It’s believed that humans possess an orienting system referred to as “global meaning,” providing a cognitive framework on which to interpret their experiences (Park, 2010, p. 257). These global meanings represent the core beliefs, goals, and subjective feelings that individuals associate with their experiences (Park, 2010). The Phenomenological paradigm provides a qualitative tool for researchers to collectively capture how individual human experiences are perceived and organized and how individuals make sense of the experiences within their life stories. “It looks at people’s everyday experiences of phenomena and how these experiences are structured, focusing the analysis on the perspective of the individual experiencing the phenomenon” (Wolff, 1999, p. 220).

Through qualitative exploration, this study provides the opportunity to delve into the unique personal stories of young and middle adult survivors of major burn injury living in the Midwestern U.S. and how participants experience and find meaning for their recovery and health. “...Investigating how people respond when they are severely burned presents an
opportunity to study an array of psychological phenomena, including acute pain control, reactions to hospitalization and medical procedures, posttraumatic stress disorder, and the influence of unusual life events on general adjustment” (Patterson, Everett, Bombardier, Questad, Lee, & Marvin, 1993, p. 362). There is potential to learn valuable information through phenomenological research that focuses on survivors’ stories, recognizing the strengths and challenges that they attribute to survival, recovery, and health (Holaday & McPherson, 1997; Lau & van Nierkerk, 2011; Moi & Gjengedal, 2008). “The profession of health education, if so inclined, is in a position to more fully encourage and support a holistic health and wellness in the populations it serves” (Moi & Gjengedal, 2008, p. 1629). Ultimately, the findings of this research hold the potential of identifying a more encompassing theoretical framework that may be used by health education providers to design, implement, and evaluate programs that target the strengths/assets identified by participants that were important to their survival and recovery from burn injury.

Purpose of the Study

The purpose of this study is to explore the psychological, emotional, spiritual, environmental, social, and vocational experiences of survival and recovery from the phenomenon of traumatic thermal burn injury and how survivors make meaning for these experiences within their life stories. Through their words we may gain an understanding of how they navigate their journey toward survival, recovery, and health/wellness following major thermal burn injury and the factors they attribute to their current health. In addition, this study will explore how survivors’ home communities may impact long-term health outcomes and quality of life.

Research Questions
1. What is the burn experience for young and middle adults living in the Midwestern region of the United States?

2. How do young and middle adult burn survivors living in the Midwestern region of the U.S. make meaning for their major burn-related recovery and health?

3. How do structural networks/communities of young and middle adult burn survivors impact their burn-related recovery, health/wellness, and quality of life?

Significance to Public Health and Health Education

This study offers an opportunity to explore the phenomenon of major thermal burn injury by providing young and middle adult burn survivor participants with a voice to tell their burn-related stories. Exploration of participants’ discourse obtained through one-on-one interviews grants a glimpse into the thoughts, beliefs, perceptions, and feelings about how they navigate their survival, recovery, and health following major thermal burn injuries. This study will also explore how participants' home communities may have impacted their health outcomes and quality of life. This study seeks to uncover and describe how adult burn survivors make meaning for their burn injuries and how they reorganize their individual life stories to accommodate this life changing event. By furthering our understanding of thermal burn injury experiences through analytical discourse with those who have survived, health educators and other providers may gain greater insight into how adult burn survivors understand the process of burn recovery, the meaning survivors attach to their burn-related experiences, and perceive their path toward recovery. We also have the potential to learn more about the personal resiliency survivors attribute to their health/wellness outcomes following major burn injury and a theoretical framework that is encompassing of the burn experience. Development of theory-driven programming that promotes optimal long-term health/wellness outcomes may then result in
improved dimensions of health/wellness, vocational reintegration, and quality of life for burn survivors in the future.

Research Design

When considering how I could obtain meaningful data to answer my research questions, I knew it was imperative to go to members of the burn community for their input. Qualitative research methods allow us to go to the source for our answers regarding a human experience. Through use of a phenomenological paradigm, I hope to capture how young and middle adult burn survivors make meaning within their life stories as they recover from their burn injuries. After gathering data through individual, face-to-face semi-structured interviews with burn survivors, their significant others, and personal observations, data will be interpreted for meaning regarding their burn injuries, survival, rehabilitation, and journey toward burn-specific health/wellness.

Merriam (2009) defines qualitative research as providing a window into how people interpret their experiences, how they construct their world, and what meaning they assign to their experiences. Phenomenology is grounded in the philosophical works of Edmund Husserl, for purposes of exploring facets of human existence beyond the physical world, and to further understanding about shared human experience (Churchill & Wertz, 2001; Merriam, 2009). “The researcher/interviewer presents herself as the listener and asks participants to give accounts of their experience of the phenomenon. She asks probing questions to encourage the participant to elaborate on the details to achieve clarity and to stay close to the lived experience” (Starks & Trinidad, 2007, p. 1375)

By drawing to the surface and gleaning “essence of the lived experience” (van Manen, 1984, p. 1) from within interview transcripts and direct observation, we have an gateway to
discover if there is a collective thought/behavioral process for how survivors make sense of their burn-related experiences, feelings, and beliefs that contribute to more positive long-term outcomes. The essence or nature of an experience has been sufficiently described within the language obtained through personal interviews when the description included reawakens or makes understandable the lived meaning or significance of the experience in a fuller or deeper manner (van Manen, 1984).

There is an advantage to being a burn survivor interviewing burn survivors for research purposes, a vantage point that has not been utilized within current literature. There is an implied understanding (Moustakas, 2001) between the participants and me in that there are some experiences and insights that are common in burn injury and don’t need to be explained, such as therapeutic procedures, the emotional and vocational consequences of social stigma, attendance at support group meetings, and awkward job interviews or blind dates. But there are also differences in that I have been pondering my research questions for a long time, and my interview questions will be new and possibly surprising and/or challenging for participants. I believe that being a member of the burn community allows me entrance into this special group of survivors in a way that may not be possible for someone who is a complete outsider, or even a provider. I will have to be very cautious not to overstep the comfort level and trust that I have with the participants, respecting their privacy and emotional stability throughout the interview process by providing a secure and trustworthy environment (Moustakas, 2001). It will be necessary for me to be rigorous with my interviewing while not making assumptions for what participants are saying that may be influenced by my own perceptions, beliefs, and feelings. Finally, as I approached this exploration, I will make a concerted effort to uncover my own
hidden thoughts and feelings about my burn experiences within my reflexivity journal. I will also take care to allow participants to verbalize their stories with a minimum of interruptions.

Participants

A non-probability, purposive sampling approach will be used to recruit burn survivor participants who were treated at SIU School of Medicine (SIUSOM)/Memorial Medical Center (MMC) regional burn center and the burn center at University of Chicago. I hope to recruit at least eight participants. With this minimum of participants, this study will be consistent with current phenomenological studies that utilized semi-structured interviews to explore in-depth descriptions of a shared phenomenon with between 6 and 15 participants (Higgins & Mansell, 2008; Lau & van Niekerk, 2011; Moi, Vindenes, & Gjengedal, 2008; Ploughman, Austin, Murdoch, Kearney, Fisk, Godwin, & Stefanelli, 2012; Ream & Richardson, 1997).

A non-probability, purposive sampling approach will be used to recruit participants from the mailing lists of the inactive burn support groups associated with the two participating regional burn centers. In addition, recruitment will be conducted at the annual burn survivor recognition dinner for one of the units. Participants will have been discharged from their respective burn units for at least one year prior to study participation to allow for “healing” of and reflection on their thermal burn experiences. To be considered for the study, participants must be between 24 and 65 years of age, have sustained a major burn injury with > 20 percent TBSA burns that include deep partial and full thickness burns to the face, hands, feet, or joints, and a minimum of 17 days of inpatient care. This TBSA and days of inpatient care criteria meet the definition for major burn injury requiring specialized burn care (ABA, 2009). The criterion is also reported to represent a threshold for decreased “general health” and perceived quality of life for burn survivors (Fauerbach, Lezotte, Hills, Gromes, Kowalske, de Lateur, Goodwin,
Blakeney, Herndon, Wiechman, Engrav, & Patterson, 2005, p. 22). Recruitment of significant others will be accomplished through participants who will be asked to identify one person who provided support through their burn recovery experience.

I’ve chosen to recruit participants that have been involved in some kind of peer support experience in the past, as indicated by attendance to at least one gathering, such as the survivor dinner or participation in another burn support network. When available, peer support groups are believed to provide members with empathy, social and informational support, as well as share coping strategies and a sense of hope for those who both give and receive support (Badger & Royse, 2010; Barnum, Snyder, Rapoff, Mani, & Thompson, 1998). All of these features have been found to be important protective factors for general self-worth and burn-related adjustment of burned children (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998). When burn survivors come together, support (self-help) opportunities provide a form of social support that fosters a feeling of normalcy and community for attendees. “The stories told and heard in this context carry the weight of shared experience, the emotional potency of common suffering, and an avenue for social learning” (Davison, Pennebaker, & Dickerson, 2000, p. 206). Even within randomly assigned study populations suffering from various illnesses and addictions, support groups were found to positively impact overall health of those who participate within the group (Davison, Pennebaker, & Dickerson, 2000). “The helping relationship established through peer support creates a sense of community that allows for redefining of the self and learning how to heal from a traumatic injury” (Badger & Royse, 2010). This leads to an assumption that attendees of burn support gatherings will experience greater overall burn-specific health than those who do not.
The two participating burn centers represent very different catchment areas. One unit is located in a mid-sized city with a primarily rural catchment area and the other located in a large metropolitan area. Both burn centers are located in the Midwestern region of the United States. I’m curious if there are differences in the burn injury experience as perceived by participants and how rehabilitation and the journey toward burn-specific health/wellness might vary based on the community structure into which the burned patient is discharged. My experiences with both adult burn survivors attending support group meetings and adolescents who attend burn camp have left me with the impression that those who return from regional burn centers to smaller, more homogeneous communities enjoy a greater level of social support, experience greater levels of social acceptance, and report higher levels of self-esteem.

The incidence of traumatic burn injuries associated with drug manufacturing of methamphetamines is quickly becoming a serious public health concern (Santos, Wilson, Hornung, Polk, Rodriguez, & Franklin, 2005). Due to the toxic nature of chemicals used in manufacturing of the drugs, patients who are injured in laboratory accidents are found to experience increased inhalation injuries, greater resuscitation requirements, and longer intubation periods than those burned patients that were not involved in drug making activities (Santos, Wilson, Hornung, Polk, Rodriguez, & Franklin, 2005). Research indicates this sub-group of burned patients is more likely to be unemployed and uninsured at time of injury, and more likely to be poly-substance abusers, complicating long-term health outcomes (Santos, Wilson, Hornung, Polk, Rodriguez, & Franklin, 2005). Additionally, those survivors of self-inflicted burn injuries and intentional burns due to abuse were also found to spend significantly more time in hospitals (Greenbaum, Donne, Wilson, & Dunn, 2004; Tarrier, Gregg, Edwards, & Dunn, 2005). These longer stays are a result of long periods for wounds to heal than those with
accidental burn injuries, complicating their long-term burn-related prognosis (Greenbaum, Donne, Wilson, & Dunn, 2004; Tarrier, Gregg, Edwards, & Dunn, 2005). Because of their unique circumstances and personal histories, burn survivors who were involved with drug manufacturing, intentional burn injuries resulting from abuse, and those with self-inflicted burn injuries will be excluded from the study sample.

I have chosen to explore the stories of young and middle adult burn survivors as their support networks and vocational challenges require different aspects of adaptation than found within child, adolescent, and older adult populations. These burn survivors are more likely to be living in their own homes where burn injuries threaten independence and autonomy after the patient is discharged from the burn unit, as wounds are still raw and burn care requires a second (and often third) person to assist with bandage changes and activities of daily living. Young and middle adults with burn scars are faced with finding and/or maintaining intimate relationships. Physical implications and limitations may be overwhelming for existing intimate relationships and may become limiting when seeking new relationships as a result of social stigma. Young and middle adults also have a developmental need to be productive within the workforce, supporting self-esteem, independence, and the ability to transcend beyond one’s individual needs. All of these challenges significantly impact quality of life for burn survivors.

Theoretical Framework

Historically, health care has focused primary clinical and research attention on patient deficits such as symptomology and pathology from the practitioners’ point of view. Current literature identifies various psychosocial skills and attributes that detract as well as support adult adjustment to burn injuries including: coping strategies (Vanderplate, 1984; Willebrand, Andersson, Gildal, & Ekselius, 2002; Kildal, Wellebrand, Andersson, Gerdin, & Ekselius,
2005), psychological adjustment (Fauerbach, Lezotte, Hills, Cromes, Kowalski, de Lateur, Goodwin, Blakeney, Herndon, Wiechman, Engrav, & Patterson, 2005; Gilboa, 2001; Noronha & Faust, 2006; Wallace, Renneberg, Ripper, German, Wind, & Jester, 2006), spirituality (Arnoldo, Hunt, Burris, Wilkerson, & Purdue, 2006; Wiechman, Askay, & Russell, 2009), and quality of life (Blades, Jones, & Munster, 1979; Lebiebici, Adam, Bagis, Tarim, Noyan, Akman, & Haberal, 2006; Moi & Gjengedal, 2008). Even taking the post-traumatic growth model (Rosenbach & Renneber, 2008) into consideration, burn care researchers have yet to identify a theoretical model that is more inclusive of the protective factors that promote burn-specific adaptation and health/wellness that are found within resilience theory. Based on the results of my pilot study, resilience theory offers the most inclusive framework that does not focus on individual deficits, but rather individual strengths that foster adjustment, health/wellness, and quality of life.

“What resilience perspective acknowledges is the dynamic, adaptational quality of resilience strengths, recognizing that they are not fixed personality characteristics that either one has or does not have, or even that the more one has is better” (Benard, 2004, p. 37). Resilience theory is increasingly recognized and acknowledged as being extremely useful within the health disciplines (McAllister & McKinnon, 2009) and is inclusive of the innate, fluid and variable personal assets important to burn-related adaptation and health (Lau & van Niekerk, 2011). “The character, trait, or situational premise of resiliency is that people possess selective strengths or assets to help them survive adversity” (Richardson, 2002, p. 309). These character traits/assets are referred to as “protective factors,” and are believed to buffer the individual from the effects of extreme challenges, enabling him/her to develop the skills necessary to continue on in the face of crisis (Benard, 2004). Protective factors include one’s sense of happiness, subjective well-
being, optimism, humor, social competence/ability to garner social support, spirituality/faith, active coping/problem solving skills, self-efficacy and goal directedness, and the ability to make meaning for the crisis within one’s life story (Badger & Royse, 2010; Benard, 2004; Richardson, 2002). Resilience theory is the model that most efficiently supports the important innate strengths identified within data provided by my pilot study participants.

Data Collection

Following approval from SIUC Office of Special Projects, Springfield Committee for Research Involving Human Subjects (SCRIHS), and University of Chicago’s human subjects’ approval, data collection will begin by shadowing burn care providers on the ten bed SIU School of Medicine (SIUSOM)/Memorial Medical Center’s (MMC) burn unit to reflect the day-to-day burn treatment and unit activities. It has been quite a while since I’ve spent time on a burn unit and the memories begun to fade. I also want to spend some time observing in the MMC Wound Clinic that provides outpatient services for discharged or community burn patients. I will focus on interactions with and among medical providers, and types of treatment that might be identified within the participants’ stories of their experiences both on the burn unit (inpatient), when utilizing the clinic (outpatient). I will also be interested in individual experiences within each patients’ home communities post injury. Because burn care is often as traumatic for burn survivors and their families as the burn injuries themselves, my observations of day to day activities will reflect many of the experiences of my participants while they were on the unit. I will include my observations on the unit within my field log as well as any personal reflections within my reflexivity journal.

Following my observations at SIUSOM/MMC’s ten bed burn unit, I will make contact with prospective study participants and individual interviews will be scheduled with burn
survivor participants and “significant others.” I hope to secure at least four burn survivor and their significant other volunteers for study participation at the survivors’ dinner, but will send recruitment letters (Appendix B) to those burn survivors on the mailing lists of those past patients who did not attend. One-on-one, semi-structured (Appendices E & F) audio recorded interviews with past MMC patients will be held in the Memorial Medical Center or a mutually agreeable location. Patients from UoC will be recruited from their patient mailing lists and interviews will be conducted on the University of Chicago campus or a mutually agreeable location.

In addition to data obtained through interviews, I also will maintain a field log relative to any observed participant non-verbal behaviors and my personal impressions. In addition, I will maintain a reflexive journal of my own thoughts and feelings regarding my participation in the research process which will be used as a data source for triangulation purposes within data analysis.

Data Analysis
All interviews will be transcribed verbatim from voice recordings and participants will be provided an opportunity to clarify data for accuracy through member checking (Patton, 2002) by sending transcripts of their interviews to participants through the U. S. Postal Service or by e-mail. Once data are reviewed by participants for accuracy, I examine data, line by line, coding for relevant content that addresses the research questions. Following initial coding, I will identify categories and themes within data, focusing on factors participants felt were important within their journey toward survival, recovery, and burn-specific health. Transcripts, categories, and themes will be checked for consistency, credibility, and trustworthiness by a colleague, Denise Demers, who is currently a doctoral candidate in the Health Education and Recreation
Department at Southern Illinois University at Carbondale. For data analysis, I will use data sources from verbatim transcripts, pilot study data, field notes, and my reflexive journal. Through utilization of multiple data sources, triangulation of data allows for greater credibility and trustworthiness of study findings.

Limitations

The following limitations should be considered when interpreting the results of this study:

1. There is a possibility that burn injury experiences recalled by participants could be influenced by subsequent events or limited recall.

2. Length of inpatient days is dependent on how well the patient responds to treatment and when the doctors make the decision to discharge, making it very difficult to rely on number of inpatient days as noted within the literature as being part of the threshold for decreased “perceived health” (Fauerbach, et al., 2005, p. 22).

2. I am a burn survivor, and therefore am likely to possess some beliefs or bias that will need to be monitored and accounted for within the findings of this research.

3. Because of my unique life experiences and training, it would be difficult to replicate this study. It has always been easy for me to talk with burn survivors in that I am considered part of their extended burn community by virtue of my own burn injuries.

4. Burn survivors may not be as eager to participate in this research as I would hope, making recruitment for participation difficult.

Delimitations
The following delimitations should be considered when interpreting the results of this study:

1. The study sample will include male and female adults from 24 to 65 years old, meeting age ranges for early and middle adult psychosocial development (Hutchison, 2010).

2. Participants will be limited to those who have sustained thermal burn injuries.

3. Participants will have attended at least one burn support event or have another burn support experience.

4. Participant burn injuries will be > 20% TBSA, with deep partial- to full-thickness tissue damage requiring grafting meeting a burn-specific measure for “major” thermal burn injury believed to represent a threshold for decreased “perceived health” (Fauerbach, et al., 2005, p. 22).

5. Length of time since participant burn injuries will be > one year, allowing survivors and significant others time to heal and process their burn-related experiences.

6. Participants will be residing within the catchment area of the Memorial Medical Center/Southern Illinois University School of Medicine Burn Unit, located in Springfield, Illinois.

7. Participants’ burn injuries will not be self-inflicted, intentional, or the result of abuse.

8. Participants’ burn injuries will not be the associated with drug manufacturing activities.

Assumptions

This study is based on the following assumptions:
1. Participants will honestly articulate important details regarding their burn injury experiences with minimal prompting.

2. Participants experience greater burn-specific health/wellness than those adults who have not participated in burn support activities.

3. Positive burn-specific health/wellness is reflective of positive quality of life.

4. Participants will be able to articulate their burn-related stories in English.

Definition of Terms

The following terms will be utilized within the study and are defined to provide further explanation:

1. Degree of thermal burn injuries are determined by the following criteria:
   - 1st degree burns superficially affect only the outer layer of skin resulting damage to the epidermis (nlm.nih.gov/medlineplus/tutorials/burns/cd99104.pdf).
   - Superficial 2nd degree partial-thickness burns damage both the epidermis and the dermis (layer underneath) often resulting in blistering and redness and heal spontaneously (Atiyeh, Gunn, & Hayek, 2005).
   - Deep 2nd degree burns require excision and may require grafting (reconstruction) much the same as 3rd degree burns (Atiyeh, Gunn, & Hayek, 2005).
   - 3rd degree burns involve damage or complete destruction of the depth of the skin and underlying soft tissue, requiring excision and grafting (Atiyeh, Gunn, & Hayek, 2005).

2. TBSA: Denotes the percentage of “total body surface area” affected by the burn injury as determined utilizing the “Rule of Nines,” “Lund and Browder” chart, or more
currently 3-D computer graphics programs such as Surface Area Graphic Evaluation (SAGE & SAGE 2) (Atiyeh, Gunn, & Hayek, 2005, p. 131).

3. Donor Sites: Areas of body from which full or partial-thickness layers of tissue are harvested (removed) from an uninjured part of the body and used to graft (close) open burn wounds.

4. Qualitative research: Subjective, inductive research methodology which provides a means to investigate complex human problems (Merriam, 2009).

5. Phenomenological paradigm: A qualitative approach allowing researchers to explore and describe the essence of a shared human experience (Neutens & Rubinson, 2009, van Manen, 2007).

6. Triangulation: Utilization of multiple methods, data sources, investigators, or multiple theories to confirm findings from within data (Merriam, 2009).

Summary

Despite the best efforts toward prevention of and education about burn injury (Brusselaers, Hoste, Montrey, Colpaert, De Waele, Vandewoude, & Blot, 2005), well over 1.25 million people in the United States are burned each year (CDC, 2011) resulting in great human mortality, morbidity, and suffering (Brusselaers, Hoste, Montrey, Colpaert, De Waele, Vandewoude, & Blot, 2005). As mortality rates decrease from major burn injury as a result of advancements in treatment modalities, greater attention has been focused to the psychosocial aspects of burn care and rehabilitation (Diefede, Cukor, Lee, & Yurt, 2009; Munster, 1980; Van Loey & Van Son, 2003).
Over the last several decades, a great deal of quantitative research has been conducted on the medical and psychological consequences of, and treatment for burn injury. To date, there have been far fewer qualitative studies that focus on the subjective experiences of traumatic burn injury survivors, their associated psychosocial challenges, and individual strengths (Williams, Doctor, Patterson, & Gibran, 2003). This study seeks to explore the personal experiences of early and middle adult burn survivors living in the Midwestern United States, aged 24 to 65, and how they navigate their journey toward survival, recovery, and burn specific health/wellness following major thermal burn injury.
CHAPTER TWO
LITERATURE REVIEW

Burn injury has always posed a significant threat to the health and wellbeing of those who come in contact with any heat/energy source. Over the past forty years, there have been incredible advancements in not only fire and burn prevention, but also within the treatment of patients with major burn injuries. Prior to the 1980’s, people who sustained greater than 33 percent deep-partial and/or full thickness thermal burn injuries were not expected to survive. Since that time, developments in transport, fluid resuscitation, and early wound excision and closure have facilitated significantly improved survival rates for devastating burn injuries (Blades, Jones, & Munster, 1979). However, as more people survived disfiguring burns, provider and research concerns were drawn to what level of adjustment and quality of life could be expected for those patients (Blades, Jones, & Munster, 1979).

Much of the psychosocially based research focused on traumatic burn injury highlights individual deficits that detract from expected quality of life, such as poor coping strategies or lack of needed social support. Current researchers have developed an empirically-testable theory that appears to satisfy many of the concerns of burn care providers regarding the future of their patients. Post-traumatic growth is grounded in the belief that patients may benefit to some extent from their traumatic burn-related experiences (Rosenbach & Renneberg, 2008). Factors that have received far less attention within current burn care literature are the innate resilient resources that are instrumental to positive long-term outcomes. Exploration and interpretation of discourse with burn survivors through face-to-face, semi-structured interviews provide an opportunity to learn more about the psychological, social, emotional, spiritual, environmental,
and vocational factors burn survivors identify as being instrumental to their survival, recovery, and burn-specific health/wellness.

Purpose of the study

The purpose of this study is to explore the psychological, emotional, spiritual, environmental, social, and vocational experiences of survival and recovery from the phenomenon of traumatic thermal burn injury and how survivors make meaning for these experiences within their life stories. Through their words we may gain an understanding of how they navigate their journey toward survival, recovery, and health/wellness following major thermal burn injury and the factors they attribute to their current health. In addition, this study will explore how survivors’ home communities may impact long-term health outcomes and quality of life.

Significance to Public Health & Health Education

The role of public health is to promote and protect the health and wellbeing of the nation’s residents, supporting positive, health-related quality of life (HHS, 2009). Burn injury resulting in disability due to disfigurement and/or loss of function challenges and often hampers survivors’ access to elements within their environment that promote quality of life. This often includes many health-related benefits that may be more readily available to the general population (HealthyPeople, 2012). To compensate for at least some of these challenges, additional social, environmental, and vocational protections are extended to survivors of disfiguring burn injury under the Americans with Disabilities Act of 1990 (PL 101-336). The goal is to equalize public access and consideration (ADA, 2009). Additional federal recognition for the health and wellbeing of burn survivors can be found within the goals of Healthy People 2020. Outlined in the leading health indicators of the plan, attention is drawn to an ongoing need
to support the health and wellbeing of those living with disabling conditions, supporting inclusion within all facets of society enjoyed by the general population (HealthyPeople, 2012). Special attention is focused on prevention of violence and injury, specifically identifying support for those impacted by fires and burns as a consideration within the national goals and objectives (HealthyPeople, 2012).

Despite substantial investments by the federal government and Centers for Disease Control and Prevention to decrease the incidence of burn injury, approximately 1.25 million Americans are burned each year. These burns result in costly and painful requiring specialized intensive care treatment, and rehabilitation. In addition to inpatient experiences, there is potential for disfigurement and disability, resulting in substantial losses in individual productivity over a lifetime. The lifetime financial burden of medical costs and loss of productivity associated with burn injuries in the US for the year 2000 was estimated at over $7.5 billion (Corso, Finkelstein, Miller, Fiebelkorn, & Zaloshnja, 2006). Burn injuries may result from dangerous or careless behaviors, or may be the result of circumstances outside the victim’s control, such as an industrial accident, crime, or residential fire. The public health burden of traumatic thermal burn injury is worsened as the number of wounded combat veterans return from war zones with major burn injuries, which are typically associated with improvised explosive device (IED) explosions and contact with other incendiary weapons.

**Burn Trauma**

Burn injury is not specific to any given population or location, affecting every age group, ethnicity, and occupation. The American Burn Association (ABA) registry provides demographics of admissions to burn units between the years of 2001 to 2010 as:

- Survival Rate: 96.1%
• Gender: 70% male, 30% female
• Ethnicity: 60% Caucasian, 19% African-American, 15% Hispanic, 6% Other
• Admission Cause: 44% fire/flame, 33% scald, 9% contact, 4% electrical, 3% chemical, 7% other
• Place of Occurrence: 68% home, 10% occupational, 7% street/highway, 15% other

Note: Table referencing data from American Burn Association National Burn Repository (2011 report)

When considering the demographics and future health-related needs of burn survivors, it also is important to recognize empirical evidence that the adult population hospitalized with major burn injuries consists of a larger proportion of people with a pre-existing history of psychopathology (Gilboa, 2001). These pre-existing conditions including depression, personality disorders, alcoholism, and drug abuse, all conditions that complicate health status (Gilboa, 2001) and long-term health outcomes.

Domestic injuries do not account for all burn-related injuries within the United States. Burn injuries account for 5 percent to 10 percent of combat casualties (White & Renz, 2008) and are not included within the domestic reports of burn unit admissions. Burn-related casualties are linked to a variety of mechanisms, including explosions related to incendiary devices and secondary fires that ignite clothing and surrounding materials following the primary explosion (White & Renz, 2008). “Despite active efforts to ensure optimal protection against flame for the combatant, the face and hands continue to be those areas least protected resulting in significant burns to these areas” (White & Renz, 2008, p. S318). Field triage shortly after injury provides assessment of complex medical issues, followed by intubation of airways (prior to pharyngeal
edema) and ventilation, resuscitation of vital fluids volumes, and excision of burn wounds; soldiers are then typically air lifted thousands of miles to an ABA accepted burn unit within the United States for acute medical treatment and rehabilitation (Renz, Cancio, Barillo, White, Albrecht, Thompson, Ennis, Wanek, King, Chungm, Wolf, & Holcomb, 2008).

The U.S. military recognizes innate resilience as a mitigating factor in positive and negative post-combat health outcomes and has implemented resilience building programs for combat-ready soldiers. The “Battlemind Training System” (U.S. Army) and the “Marine Corps Resilience Program” (U.S. Marine Corps) provide mental health support in the form of “generic” power point presentations directed toward combat stress (Castro & Adler, 2011, p. 323). These interventions are provided prior to soldiers being deployed and again after soldiers’ return to home base and before discharge (Castro & Adler, 2011). However, there are currently no empirically tested programs that are designed specifically to promote resilience for burned soldiers (Castro & Adler, 2011).

Progress in burn treatment over the past several decades has been phenomenal, with decreased mortality rates of burned patients believed to be attributed to coordinated efforts of increased national awareness, medical advancements in acute burn treatment, and public health efforts in fire and burn prevention (Brigham & McLaughlin, 1996; Esselman, 2007). In an effort to address the geographic challenges of acute burn care management, over 125 self-identified regional burn treatment centers (only 51 are recognized by the American Burn Association) have been established to address the intensive burn care needs of almost every major U.S. city and its surrounding counties. These units are believed to provide approximately (80%) of the public access to a specialized intensive care burn unit within two air-time hours in an emergency (Klein, Kramer, Nelson, Rivera, Gibron, & Concannon, 2009).
Burn treatment units are labor and cost intensive, and are typically supported by both public and private funding. Length of stay (LoS) for patients on a burn unit for operative burns between (10%) to (20%) TBSA averaged between 12.9 to 16.6 and 28.9 to 32.3 in-patient days respectively, with a per diem rate of approximately $1,663 (Jansen, Hynes, Macadam, & Papp, 2012). These estimates do not take into account complicating factors such as smoke inhalation/poisoning which occurs in approximately (10%) of all thermal burns (Esselman, 2007), sepsis (Falder et al., 2009), and other complicating injuries (White & Renz, 2008). For those who lack sufficient insurance coverage and/or financial resources, the economic burden associated with burn-related treatment, rehabilitation, and possible disability must then be carried by American taxpayers.

The Medical Model

The medical model, the most widely accepted conceptual model used within the health professions, originated with the teacher and philosopher Hippocrates. The model was then further developed through the work of Descartes in the 16th century, at which time he likened the human body to the workings of a machine (Larson, 1999). The goal of the medical practitioner within this framework is to identify the dysfunctional component/s within the physical system of the patient, supporting the distinction between disease, illness, and health (Wood, 1986). Illness is the definition for what the patient believes is causing their physical distress (Larson, 1999). Disease, on the other hand, is based on the practitioners’ perception and grounded on an identifiable and consistent disturbance within the body (Larson, 1999).

The World Health Organization (WHO) defines impairment as any loss or abnormality of psychological or physical structures or function (Fauerbach, Engrav, Kowalske, Byrch, Bryant, Lawrence, Li, Munster, & de Lateur, 2001). The definition of disability within the United States
has a much stronger emphasis on clinical diagnosis, indicating alterations within the survivors’ ability to meet personal, social, and occupational needs (Fauerbach, et al., 2001). This distinction makes a definition of health within disabled populations difficult to ascertain (Brisenden, 1986). With growing numbers of people surviving acute illness and injury, there are equally increasing numbers of Americans being treated for chronic, often disabling conditions that relate directly to the acute episode, such as major burn injury. The medical model focuses on individual deficits that contribute to disease and disability rather than strengths that promote health and wellness (Askay & Russell, 2009). This approach often leads to socially inhibiting or exclusionary practices that disqualify the person from those social, environmental, and vocational benefits available to the general public (Brisenden, 1986; Larson, 1999; Wood, 1986).

As with any profession, there is value in a shared language and protocols, and medicine is no exception. Within the confines of an intensive-care burn treatment unit, the medical model provides structure and continuity of care, with treatment modalities rooted in scientific inquiry and evaluation. Improved communication with patients and family may be facilitated by sharing meaning for terms and protocols utilized within this unfamiliar environment. “Along with the family, the patient needs help to understand the new country and its culture, to learn the language and the customs…” (Partridge & Robinson, 1995) Once patient survival is established, there is a transition from acute phase to healing phase, when sole use of the medical model may become limiting by continuing focus on individual burn-related health deficits rather than individual strengths. As burn survivors begin their journey toward recovery and burn-specific health, challenges to psychological, social, emotional, environmental, spiritual, and vocation dimensions of health become equally as important as the physical dimension of health that focuses purely on the biological functioning of the body.
Shifting focus of patient treatment to include all dimensions of health and wellness provides a framework on which to base health-specific interventions and education that more fully utilize patients’ psychosocial assets. “Momentum has developed to concentrate professional practice on coping rather than on risk, on opportunity rather than on fatalism, on wellness and self-repair rather than on illness and disability” (Norman, 2000, p. 1). Utilization of resilient psychosocial assets within a healthcare model directs attention beyond patients’ physical dimension of health, and recognizes the benefit of a holistic approach to burn patient rehabilitation and burn-specific health. Future health-related programming focused on strengthening innate resilient attributes or factors may make the difference between becoming a “survivor” of traumatic thermal burn injury versus a “victim,” thereby promoting improved quality of life.

Quality of Life

The Centers for Disease Control and Prevention define quality of life (QoL) as a multidimensional concept that typically encompasses subjective evaluations of both positive and negative aspects of life (CDC, 2011). The World Health Organization (WHO) adds the importance of individual evaluation of quality of life in the context of the culture and value systems in which the person lives, their personal goals, expectations, standards, and concerns (WHO, 2012). The concept of individual health-related quality of life (HRQOL) incorporates the importance individual physical and mental health perceptions and their correlates, including health conditions and risks, functional capacity, social support, and socioeconomic status (CDC, 2011). On a community level, HRQOL includes resources, policies, conditions, and practices that influence a population’s perception of health and functional status, allowing health-based agencies to legitimately address broad areas of health-related public policy (CDC, 2011).
Prior to the 1980’s, survival was the mark of success for burn trauma patients with little attention given to long-term health outcomes or quality of life and limited possibilities for reconstruction of burn injuries. Beyond the physical parameters of illness, burn injuries are found to create disturbances in social participation through both functional and aesthetic impairment (Falder, et al., 2006). The goal of burn treatment today incorporates the importance of returning the burned person to their previous life roles with equal potential and an acceptable level of social reintegration (Falder, et al., 2006). This level of reintegration includes the many vital components of quality of life available to the general population (Falder, et al., 2006).

Through a team approach to clinical care, doctors, nurses, social workers, psychologists, psychiatrists, spiritual advisors, occupational therapists, respiratory therapists, and rehabilitation experts are included within the clinical treatment group in an attempt to improve the chances for optimal quality of life in those patients who survive their burn injuries, as well as their families (Munster, 1980).

Within a study examining health-related quality of life, Gaynes, Burns, Tweed, & Erickson (2002) examined three discrete domains of patients’ health functioning in relation to multiple chronic conditions, including type II diabetes, hypertension, and arthritis: physical functioning (mobility and physical activity), role functioning (including self-care), and health problems (visual and hearing problems, pain associated the chronic condition). Within these conditions, depression was found to decrease quality of life. Comparable decreases in quality of life were attributed to participants’ co-morbid condition when measured independently and compounds those decreases in patients’ quality of life when disorders are considered together (Gaynes, Burns, Tweed, & Erickson, 2002).
Researchers have attempted to quantify QoL for burn survivors through empirical scales such as the burn specific health scale (BSHS) (Bernstein, O’Connell, & Chedekel, 1992; Druery, Brown, & Muller, 2005; Edgar, Dawson, Hankey, Phillips, & Wood, 2010). However, there have been few attempts to qualitatively explore the subjective accounts of individual meanings relative to bodily changes in the context of everyday life experiences of adult burn injured people in the United States, and how those changes impact their quality of life (Holaday & McPherson, 1997; Morse & Carter, 1995; Morse & Mitcham, 1998; Williams, et al., 2003). Some current qualitative studies explore the burn event and its consequences as experienced by adult burn survivors in terms of both losses and gains, including identity, social roles, lifestyle, interpersonal relationships, and physical functioning (Moi, Vindenes, & Gjengedal, 2008). With the exception of Morse & Carter (1995) and Lau & van Niekerk (2011) who utilize narrative frameworks to qualitatively explore the stories of young burn survivors, there are no burn-related researchers who refer to specific psychosocial or health-related theories to support their findings.

Functional Impact of Burn Trauma

Functional limitations due to chronic neuropathic burn pain (Dauber, Osgood, Breslau, Vernon, & Carr, 2002; Summer, Puntillo, Miaskowski, Green, & Levine, 2007), loss of sensation (Falder, et al., 2009), scarred, tight, and fragile tissue (Moi, Vindenes, & Gjengedal, 2008; Van Loey, Faber, & Taal, 2001), and inhibited joint range of motion (RoM) due to contractures (Leblebici, Adam, Bagis, Tarim, Noyan, Akman, & Haberal, 2006; van Baar, Essink-Bot, Oen, Dokter, Boxma, & van Beeck, 2006) are frequent consequences of major thermal burn injury. RoM-limiting contractures impact approximately 30 percent of adult burn patients with a mean total body surface area (TBSA) of 20 percent at discharge, and functional losses reported as
higher than 18 percent five years post-injury (van Baar, Essink-Bot, Oen, Dokter, Boxma, van Beeck, 2006).

Skin plasticity may also be impacted by hypertrophic scarring which impacts survivors on multiple levels (Falder, et al., 2009). “Hypertrophic scarring is characterized by red, raised, and rigid scar tissue that contracts and limits normal motion of the skin” (Esselman, 2007, p. S3). This abnormal scarring is particularly problematic when formation occurs on the hands inhibiting manual dexterity, the legs restricting ambulation, and the neck that constrict head movement. Amputation of extremities is necessary when soft tissue damage is deemed irreparable, impacting between 2 percent (Mean TBSA 12%) and 46 percent (Mean TBSA > 80%) of burn patients (van Baar, Essink-Bot, Oen, Dokter, Boxa, & van Beeck, 2006). Even years after the acute phase of treatment, burn-related scar tissue and grafted areas remain stiff and/or fragile, and are sensitive to temperature and sun, impacting burn survivors’ ability to work or participate in activities outdoors in extreme temperatures.

With decreased mortality of burned patients, researchers are focusing greater attention on functional outcomes of major burn injury. The focus includes burn-related physical dysfunction that may inhibit survivors’ employability, a factor believed to be a vital representation of adaptation, normalcy, and an acceptable level of quality of life (Dyster-Aas, Kildal, Willebrand, Gerden, & Ekselius, 2004; Falder, et al., 2009; Leblebici, Adam, Bagis, Tarim, Noyan, Akman, & Haberal, 2006; Oster, Kildal, & Ekselius, 2010). The relationship between physical, psychological, and environmental dynamics affecting return to work (RTW) following major burn injury are not well understood by burn care providers (Oster, Kildal, & Ekselius, 2010). Providers would benefit from more in-depth attention to individual survivor perspectives
regarding barriers and supportive factors that contribute to RTW (Oster, Kildal, & Ekselius, 2010).

“Return to work (RTW) after burn injury is an important part of the recovery process, adaptation, and being a member of the community” (Oster, Kildal, Ekselius, 2010, p. 540). Major burn injury causes significant barriers to return to work including contractures, neuropathic pain, amputations, weakness, and psychosocial issues including body image disturbances, fear, depression, anxiety, and symptoms associated with post-traumatic stress (Esselman, Askay, Carougher, Lezotte, Holavanahalli, Magyar-Russell, Fauerbach, & Engrav, 2007). Multiple variables influence a person’s ability to return to work after major burn injuries, including:

• Age at time of injury;
• Pre-injury level of functioning (including pre-burn employment status);
• Severity of burn injuries (TBSA);
• Facial and/or extremity burns;
• Psychiatric history;
• Medical history;
• Pre-injury substance use;
• Level of pre-injury job satisfaction;
• Time since treatment;
• Insurance status;
• Injury-related litigation;
• Loss of property;
• Loss of co-workers, friends and/or family members in the burn event (Dyster-Aas, Kildal, Willebrand, Gerden, & Ekselius, 2004; Esselman, et al., 2007; Fauerbach, et al., 2001; Oster, Kildal, & Ekselius, 2010).

Within burn care literature, severity of injuries is deemed the most important variable impacting RTW (Esselman, et al., 2007; Fauerbach, et al., 2001; Oster, Kildal, & Ekselius, 2010).

Of those adults who were employed at the time of burn injury, between 30 percent and 42 percent of patients were burned on the job (Esselman, et al., 2007). These injuries often include hand burns requiring difficult reconstructive surgery that directly impacts ability to return to work (RTW) (Esselman, et al., 2007). However, despite these psychosocial and functional limitations, approximately 70 percent of survivors with severe burn injuries in the U.S. who were employed prior to their injuries, returned to work (Esselman, et al., 2007). Important individual traits contributing to RTW within a Swedish study found willpower, determination, motivation, optimism, self-efficacy, and goal-directedness as being most important psychosocial factors influencing RTW (Oster, Kildal, Ekselius, 2010). All of the individual traits that support RTW within the Swedish study are consistent with protective assets/factors identified within resilience theory.

RTW following burn injury may be a complicated process, and may be initiated within early interventions (Esselman, et al., 2007) for both in- and out-patients, as well as those burn survivors living within the burn centers’ catchment area. Support and coordination of multiple stakeholders may be necessary, including the employee and his/her family, the employer, the health care system, and the insurance/workman’s compensation system, as well as necessary workplace accommodations (Esselman, et al., 2007). Patients who were unemployed prior to their burn injury (Oster, Kildal, & Ekselius, 2010; van Baar, Essink-Bot, Oen, Dokter, Boxma,
van Beeck, 2006), tested positive for substances at time of admission (Fauerbach, et al., 2001), and/or those with pre-morbid mental health histories (Dyster-Aas, Kildal, Willebrand, Gerden, & Ekselius, 2004; Esselman, et al., 2007) are believed to be least likely to secure gainful employment following burn treatment without substantial intervention.

While historically the medical model has been used to measure disability and degree of dysfunction within the body, the Americans with Disabilities Act (PL 101-336) extends additional protection in the public sector for “perceived” disability of burn survivors with visible disfigurement (ADA, 2009). The definition of disability used in PL 101-336 takes into consideration the fact that disability is to some extent a matter of social perception (Gammon & Abrams, 1993). The law protects access to jobs which involve contact with the public that have been denied to burn survivors in the past because of their disfiguring scars (Gammon & Abrams, 1993). The amended Americans’ with Disabilities Act of 2009 defines disability as a physical or mental impairment that substantially limits one or more major life activities or bodily functions, a record of that impairment, or an incident in which the burn survivor was perceived to be unable to perform certain functions of a job as a result of his or her physical appearance (ADA, 2009).

Interference with major life activities may be described as difficulty caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working (ADA, 2009). Interference with bodily functions include functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions (ADA, 2009). Evaluation of disability for burned patients is complex in that there are multiple physical and psychosocial factors to consider (Chang & Herzog, 1976). Physical limitations due to contractures, and psychological factors such as
depression, post-traumatic stress, concerns regarding appearance, and fear of failure are just a few barriers burn survivors have to overcome when they consider return to work (Chang & Herzog, 1976). It has also been suggested there are additional “medico-legal gains” and other incentive factors that may prevent or hinder the burn survivor’s return to work (Chang & Herzog, 1976, p. 36). In the event that a burn survivor is not able to return to his/her previous position due to physical limitations, they may become eligible for Social Security Disability Insurance (SSDI). Many of those individuals receiving SSDI may have greater earning potential through their disability insurance than to secure a lesser paying job, leaving the potential worker to feel excluded and unproductive.

Once the burn patient returns home from the hospital, there is continued need for wound care and bandage changes that are often provided by a home health nurse. A Jobst pressure garment [a heavy elasticized compression garment] is typically worn for approximately one year post-burn injury to control for contractures and hypertrophic scarring, but remains dependent on the total body surface area (TBSA) injured. Survivors with greater TBSA burn injuries may require them to wear the garments much longer. As wounds heal and the burn survivor is faced with loss of function, there is a greater risk for the survivor to become socially withdrawn, reclusive, and shy (Chang & Herzog, 1976). Chronic pain and poor psychological functioning are believed to be the most common cause of disability within burn injury studies (Dyer-Aas, Kildal, Wellebrand, Gerdin, & Ekselius, 2004). As found with other chronic, disabling health conditions, it is important for burn survivors who are not in the workforce to become engaged in some kind of intimate social relationships and productive activities. The involvement supports survivors’ developmental challenges of young and middle adulthood. This productive work may be in the form of part-time employment or volunteer activities.
Psychosocial Impact of Burn Trauma

Physical appearance provides a number of unspoken messages to others about who we believe we are and where we have been. Beyond the functional characteristics of the skin, there are important psychosocial, aesthetic functions that represent our identity, self-image, and self-concept (Oster, Kildal, & Ekselius, 2010). “At discharge 37 percent of patients had problems with their appearance (mean TBSA 30.2%); 43 percent reported having problems with respect at fifteen weeks post-burn (mean TBSA 4%), and 14 percent of patients reported problems with their appearance at least one year post-burn (mean TBSA 5%)” (van Baar, Essink-Bot, Oen, Dokter, Boxma, & van Beeck, 2006, p. 6). These problems may be relative to how burn survivors perceive their own appearance as well as how they are perceived by others (Moi, Vindenes, & Gjengedal, 2008). Burn survivors who have visible scars are often subject to scrutiny in the form of social stigma. Social stigma refers to a social/cultural perception of deviance from prevalent or valued social norms, leaving the person who is stigmatized as negatively different (Bernstein, O’Connell, & Chedekel, 1992; Grytten & Maseide, 2005; Thompson & Kent, 2001). Social stigma is also believed to negatively impact return to work post-injury (Oster, Kildal, & Ekselius, 2010; van Baar, Essink-Bot, Oen, Dokter, Boxma, & van Beeck, 2006). Those with facial disfigurements are subject to greater scrutiny, placing greater reliance on the survivors’ ability to engage socially with others (Macgregor, 1990).

Within every culture, there are agreed upon norms and mores that influence our perception of beauty (Partridge & Robinson, 1995) and guide social interactions with strangers. These norms include proper eye contact that is neither fleeting nor fixed, rules regarding personal space, asking prematurely intimate questions, and avoiding topics that are likely to be inappropriate or embarrassing (Macgregor, 1990). In American culture, scars are seen as
detractive when evaluating beauty, and often draw unwelcome attention. The anonymity afforded those without disfigurement is often denied those that cannot conceal their burn scars. These survivors must go about their daily lives experiencing a level of familiarity from strangers that would be considered inappropriate under any circumstances, including stares, startled looks, whispers, remarks, pointing, curiosity, personal questions, ridicule, and avoidance; all circumstances that impact survivors’ psychosocial health and quality of life (Fauerbach, et al., 2005; Leblebici, et al., 2006; Macgregor, 1990; Moi, Vindenes, & Gjengedal, 2008; Partridge & Robinson, 1995; van Baar, Essink-Bot, Oen, Dokter, Boxma, & van Beeck, 2006). Changes in physical appearance caused by burn injuries are seen, felt, and perceived by the burn survivor as a reminder of their burn event and subsequent pain/trauma of hospitalization that ultimately disrupted their life story (Moi, Vindenes, & Gjengedal, 2008).

Depression is believed to be a co-morbid condition in one fourth to one third of medically hospitalized patients (Gaynes, Burns, Tweed, & Erickson, 2002). The comorbidity is a concern for a variety of reasons. People with a pre-existing affective and somatic depressive symptomology are more likely to become ill than the general population, and are also more likely to remain ill, resulting in poor treatment outcomes (Gaynes, Burns, Tweed, & Erickson, 2002). Complicating long-term health outcomes, depressive symptoms have also been found to exacerbate disabilities associated with physical illness including the domains of social functioning, productivity, physical functioning, and self-care (Gaynes, Burns, Tweed, & Erickson, 2002).

While early burn care research indicates minimal long-term psychological consequence to major burn injury, conflicting reports regarding burn-specific health have evolved over time (Kleve & Robinson, 1999). Current long-term follow-up studies of burned patients indicated a
higher prevalence of depression and anxiety disorders than found in the general population, affecting between seven to forty-six percent of burn patients during and after hospitalization (Falder, et al., 2009). Issues related to anxiety and symptoms of post-traumatic stress disorder (PTSD) are consistently reported as an important rehabilitative consideration within existing burn-care literature, requiring additional long-term resources and support for affected burn survivors (Esselman, 2007; Van Loey, Faber, & Taal, 2001; Noronha & Faust, 2006; Willebrand, Andersson, & Kildal, 2002). Traumatic memories, disturbed sleep patterns, nightmares of the burn event, and trauma from acute burn treatments of debridement, hydrotherapy, physical therapy, and painful bandage changes frequently follow burned patients long after discharge (Bernstein, O’Connell, & Chedekel, 1992; Low, Dyster-Aas, Willebrand, Kildal, Gerdin, & Ekselius, 2003). Feelings of social withdrawal, anger, hostility (Bernstein, O’Connell, & Chedekel, 1992), vulnerability, helplessness, poor self-esteem (Moi, Vindenes, & Gjengedal, 2008), and loss of hope for the future (Morse & Carter, 1995) following the burn event contribute to depressive and anxious feelings both during hospitalization and after. Whether anger is turned outward as aggression or inward as depression, these findings support the value of supportive psychosocial interventions for burn survivors for an extended period following hospitalization (Kleve & Robinson, 1999; Van Loey, Farber, & Taal, 2001).

One’s ability to cope with extreme crisis requires both internal as well as external supports. “Coping refers to a person’s cognitive and behavioral efforts to manage stressful situations and accompanying negative emotions” (Kildal, Willebrand, Andersson, Gerdin, & Ekselius, 2005, p. 511). While it might not seem surprising for someone severely injured and hospitalized to be faced with unexpected challenges to individual and family coping skills, burn
patients are confronted with unique and difficult issues that play important roles within survivors’ successful adaptation.

“Unlike the effects of other injuries or illnesses which may be short-lived, follow a course to resolution, or be amenable to treatment, the scarring and disfigurement of severe burn injury are permanent. The irreversible alterations in appearance may be an assault upon body image and self-esteem perhaps more potentially devastating than with most injuries or physical illnesses” (Vanderplate, 1984, p. 333).

Low, et al., (2005) reported that coping strategies are rooted within individuals’ personalities and can be typically be divided into two main groups; attempts to avoid the stressful situation or event and attempts to approach the situation or event. The internal factors that promote resilience are believed to be more rooted in sustainability from an injury or trauma, rather than recovery (Zautra, Hall, & Murray, 2010) which may be more realistic for burn survivors. However, for providers to encourage sustainability, we must be aware enough of individual assets and goals that give patients’ lives meaning beyond mere survival (Zautra, Hall, & Murray, 2010).

Much of the psychosocial burn-care literature placed emphasis on individual personality traits and deficits within the patient’s ability to cope with acute and rehabilitative issues surrounding painful burn-care (Vanderplate, 1984). Treatments, surgeries, confusion, isolation, grief, and symptoms of post-traumatic stress have been found to affect as high as 56 percent of burn patients (Low, et al., 2005). Somatic complaints plague more than 90 percent of burn patients long after discharge (Willebrand, Kildal, Ekselius. Gerdin, & Andersson, 2001).

Fauerbach, et al. (2005), identified a strong correlation between patients’ subjective perception
of severity of their burns and long-term adaptation to injury and quality of life. Current literature identified specific protective factors consistent within resilience theory that promote effective coping strategies in burn patients during both the acute and rehabilitative phases (Willebrand, Kildal, Ekselius, Gerdin, & Andersson, 2001), but stop short of addressing any theory-based, long-term interventions to promote resilience in burn-injured persons.

“Many studies have focused on the psychological problems and distress among burn patients, but the resources and strengths of these patients have received much less attention, although the latter factors can help patients to face the challenges of a burn injury and its consequences” (Wallis, Renneberg, Ripper, Germann, Wind, & Jester, 2006, p. 735).

The emergence of resiliency research represents a beginning paradigm shift in which researchers are acknowledging that experience of difficulty does not necessarily result in deficient adaptation and psychopathology but rather, may more often convey adaptive resilience (Kent & Davis, 2010; Beasley, Thompson, & Davidson, 2003). Researchers for other potentially disabling conditions such as Multiple Sclerosis, arthritis, and cancer have utilized resilience as a theoretical framework within their studies and interventions. Could the relative youth of successful burn treatment and reconstruction lead to greater provider trust in quantitative data as opposed to qualitative methods that are tailored to explore burn survivors’ lived experience? And, could those same providers be self-limiting by neglecting a more inclusive theoretical approach to research?

Protective Factors

There is a bio-chemical relationship between stress and coping patterns in human brain chemistry and circuitry that is critical for stress response as the brain regulates memory function,
response to fear, adaptive social behaviors, and plays a central role in stress resilience (Ozbay, Fitterling, Charney, & Southwick, 2008). When a person experiences a perceived threat, the sympathetic nervous system (SNS) releases endorphins to facilitate self-protective behaviors, increasing the risk for chronic anxiety, hypervigilence, and other symptoms of PTSD (Ozbay, Fitterling, Charney, & Southwick, 2008). When the threat continues for an extended period of time, the SNS overreacts, increasing the risk of incapacity, anxiety, and fear (Ozbay, Fitterling, Charney, & Southwick, 2008). In addition, increasing levels of cortisol are released into the system, resulting in increased arousal, selective attention, mobilization of energy stores, and memory consolidation (Ozbay, Fitterling, Charney, & Southwick, 2008). Over prolonged periods of stress, higher levels of cortisol within the system negatively impact certain immune responses and break down muscle fibers. Cortisol is also believed to negatively affect certain regions of the brain that are important to stress response, and is linked to major depression and PTSD (Ozbay, Fitterling, Charney, & Southwick, 2008). Psychologically resilient people are believed to maintain higher SNS activation in the presence of stressful situations that respond appropriately to the perceived threat (Ozbay, Fitterling, Charney, & Southwick, 2008).

It is believed there is a positive correlation between social support and optimistic self-beliefs in burn patients (Willebrand, Kildal, Gerdin, & Andersson, 2001). These same protective factors are believed to benefit patient compliance with medical procedures that, often result in improved long-term health outcomes (Wallis, Renneberg, Ripper, Germann, Wind, & Jester, 2006). Authors agree that achieving a sense of belonging within one’s social group or community is believed to be a powerful force in sustaining the self in the face of adversity (Fine, 1991), such as experienced with the consequences of major burn injury (Badger & Royse, 2010; Moi, Vindenes, & Gjengedal, 2008). Social support is defined as access to tangible and
intangible resources, creating a buffering effect to perceived threat, supporting health and wellbeing (Cohn & Syme, 1985). Within relationships, there are mediating factors that occur when an individual assesses the availability to resources that may “buffer” the response to stressful events (Cohn & Syme, 1985, p. 6).

Buffering effects are derived from reciprocal engagement within a group and/or community, accessing both relational and tangible resources (Cohn & Syme, 1985). When the burn survivor is able to fully reintegrate within her/his social network, there is an opportunity to renew trust and reciprocity that may have been absent during hospitalization. Regional trauma centers are often inaccessible for much of the patient’s social network. There is also the belief that social networks may be more successful providing short-term support (Cohn & Syme, 1985), and that the long-term support needed in response to major thermal burn injuries may be too taxing for existing social networks (Cohn & Syme, 1985; Badger & Royse, 2010). By encouraging and supporting participation within an accessible social network during both the healing and the rehabilitative phases, whether through family support, community building, and/or participation in a burn survivor support group or intervention, the act of participation within a social network increases a sense of belonging, normalcy, self-esteem, and ultimately, quality of life for burn survivors (Cohn & Syme, 1985).

“Previous research has shown that when burn patients are given an opportunity to talk about what helps them cope, they frequently credit their religious faith or God” (Arnoldo, Hunt, Burris, Wilkerson, & Purdue, 2006, p. 923). While it is important to thoroughly explore and evaluate the distress and negative affect of patients following burn trauma, it is equally important to discover their positive emotions and growth that often accompany trauma (Askay & Magyar-Russell, 2009). As burn patients struggle to survive, then make meaning of their burn
experiences, several psychosocial factors are believed to be strongly associated with post-traumatic growth (PTG) (Askay & Magyar-Russell, 2009; Rosenbach & Renneberg, 2008). “Other terms have been used to refer to similar concepts of positive psychology, including adversarial growth, benefit finding, optimism, hardiness, and resiliency” (Askay & Magyar-Russell, 2009, p. 571). This individual growth potential may be reflected in a greater appreciation for life and social networks; changes in priorities; more intimate relationships with others; a greater sense of personal capacity; hope for the future; and spiritual development (Askay & Magyar-Russell, 2009; Rosenbach & Renneberg, 2008).

Several burn-related studies attributed supportive growth factors associated with post-traumatic growth (PTG) in burn patients to date. Rosenbach & Renneberg (1998) attempted to identify individual growth in burn patients in Germany approximately three months following discharge. They found their participant sample self-reported high levels of PTG as a whole, but also reported high levels of distress and lower quality of life (Rosenbach & Renneberg, 1998). Higher levels of education achieved and financial stability are also predictive of burn survivor PTG (Askay & Magyar-Russell, 2009). Variables that influence PTG are believed to be personality traits such as extraversion, openness, agreeableness, contentiousness are believed to be positively correlated with PTG (Askay & Magyar-Russell, 2009). Additionally, insight, use of humor, and intrinsic spiritual beliefs are also found to be variables for PTG (Askay & Magyar-Russell, 2009). These traits are consistent with those individual strengths/assets identified within resilience theory.

Mention of resilient capacities in burn-related literature is often buried within the discussion section of the literature when addressing psychosocial outcomes and coping skills (Gilboa, 2001; Kildal, Willebrand, Andersson, Gerdin, & Ekselius, 2005; Wallis, Renneberg,
Ripper, German, Wind, & Jester, 2006), citing one of only a few peer-reviewed articles that identify resilient protective factors within burn injured populations (Holaday & McPhearson, 1997; Holaday & Terrell, 1994). Holaday & McPhearson (1997) spoke to the resilient capacities of their study participants and the correlation between resiliency and positive adaptation to their burns. They inferred, “When compared with children judged as non-resilient, resilient children had higher self-regard, revealed better interpersonal skills, viewed other people as more cooperative, and were able to tolerate and control stress” (Holaday & McPhearson, 1997, p. 346). The authors concluded that resilient burn survivors possess the ability to maintain positive self-regard in the face of negative feedback, have a positive and courageous attitude, strong personal integrity, and an ability to self-protect (Holaday & McPhearson, 1997). These traits are also consistent with the protective factors identified within resilience theory.

Authors have explored the meaning-making of various age groups of burn survivors utilizing narrative and case study paradigms, reflecting how patients perceive their physical healing, social reintegration, and reconstruction of self (Bernstein, O’Connell, & Chedekel, 1992; Lau & van Niekerk, 2011; Moi & Gjenedal, 2008; Moi, Vindenes, & Gjenedal, 2008; Morse & Carter, 1995; Morse & Carter, 1995). With the exception of one early study (Bernstein, O’Connell, & Chedekel, 1992), qualitative studies were published within alternate health journals as opposed to journals specifically directed toward burn-related care. By limiting publication in burn related journals, we are in essence limiting access for busy providers who might not be aware of this new thread of literature and the potential it holds for supporting improved long-term health outcomes for burn survivors. Qualitative researchers advise that reliance on objective measures and scales within burn care research are less suited to exploring the personal, social, cultural, spiritual, and other meanings and constructs in relation to the “burn
identity” (Lau & van Niekerk, 2011, p. 1166). Is there risk in breaking away from the deficit-laden medical model when working within the burn care arena, even though researchers have identified value in resilient factors such as social support, optimism, goal-directedness, and positive self-efficacy?

Resilience Theory

The theoretical framework for this study is grounded in resilience theory (Benard, 2004; Richardson, 2002). Resilience theory grew from a foundation in phenomenological research, supporting inquiry into character strengths, traits that people possess, or situational factors of resilience that help them survive and overcome adversity (Richardson, 2002). Resilience may be observed and supported vicariously through stories of people who have survived traumatic ordeals and managed to thrive in spite of them (Frankl, 1963). Or, the experiences initiating resilient factors may be very personal. The formal study of resilience as it relates to health was initiated within epidemiological studies investigating susceptibility to heart disease in the Framingham study (Fine, 1991). There has been some controversy between theorists as to whether resilience is an intrinsic or acquired trait. Benard (2004) cited resilience is intrinsic and acts as a self-regulating factor toward survival; “…resilience skills are intrinsically motivated, biologically driven, and culturally expressed” (p. 39). Today, there is an emerging paradigm shift from the traditional problem-based theoretical approach that fosters passive human agency, to promoting strengths through encouragement of active human agency (Windle, 1999). The shift is becoming a prevalent theme within academia (Richardson, 2002), but more slowly within the helping professions, as burn care researchers alluded to resilience within their text but few as a primary investigative focus.
There are two orientations to resilience theory that address differing approaches to research, process and outcome. These approaches answer important questions:

- “Should resilience be defined in terms the nature of the outcome in response to stress or in terms of the factors which interact with stress to produce the outcomes?” (Kaplan, 1999, p. 19).
- “Is resilience the variation in good outcomes among individuals who are at risk for bad outcomes, or is resilience the qualities possessed by individuals that enable them to have good outcomes?” (Kaplan, 1999, p. 19).

Resilience as an outcome variable is defined as a way of achieving culturally normative, valued outcomes in the face of adversity, such as maintaining adaptive functioning in spite of difficult or hazardous circumstances (Kaplan, 1999). This could be applicable within groups such as adolescents growing up in abusive environments, yet go on to thrive in adulthood (Kaplan, 1999). Within this paradigm, risk factors and protective factors are directly tied to outcomes. Risk factors refer to negative predictor variables that are likely to influence negative outcomes; protective factors refer to positive predictors that are believed to mediate negative outcomes in the presence of risks (Kaplan, 1999).

Resilience as a process variable emphasizes the impact of protective characteristics and mechanisms that support positive outcomes in the presence of risk factors (Kaplan, 1999). Resilient protective factors may be characterized by cognitive and behavioral coping skills, and successful recruitment of support from one’s social network (Fine, 1991). Individual characteristics noted in literature vary but relate specifically to individual and group strengths. Individual resilient factors are believed to be:

- Social competence
- Responsiveness
- Communication skills
- Empathy & caring
- Compassion, altruism, and forgiveness

- Problem solving skills
  - Ability to make and achieve plans
  - Flexibility
  - Resourcefulness
  - Critical thinking and insight

- Autonomy
  - Positive identity
  - Internal locus of control and initiative
  - Self-efficacy and mastery
  - Adaptive distancing and resistance
  - Self-awareness and mindfulness
  - Sense of humor

- Sense of purpose and hope for the future
  - Goal direction, achievement motivation, and educational aspirations
  - Special interests and imagination
  - Optimism and hope
  - Faith spirituality and sense of meaning

(Benard, 2004).
There is some controversy as to the construct of resilience being accepted as a theory due to varying definitions of the model (Luthar, Cicchetti, & Becker, 2007). Despite these varying definitions, two essential constructs are central to resilience: 1) risk or adversity and; 2) positive adaptation or competence (Luthar & Cushing, 1999). Researchers concluded that resilience theory has merit and is applicable across the lifespan and that scientific inquiry on resilience possesses great potential for augmenting the understanding psychosocial processes of at-risk individuals (Luthar, Cicchetti & Becker, 2007; Luthar & Cushing, 1999).

Burn survivors are forced to draw on resilient factors on a daily basis without ever achieving the physical form or the life they had prior to their burn injuries (Holaday & McPhearson, 1997). For the purposes of this research, I will focus on process resilience in young and middle adult burn survivors living in the Midwestern United States, based on the findings of the pilot study for this project.

Summary

With advancing survival rates of burn patients over the past several decades, attention to psychosocial factors following severe burn injury has increased. Within burn-related literature, scholars identified several psychosocial assets that promote positive outcomes including social support and optimism, however only a few studies directly include resilience as a factor within burn patient recovery. The few qualitative studies identifying resilience in burn survivors are focused more frequently on child and adolescent populations (Holaday & McPhearson, 1997) and adults living outside of the U.S. (Lau & van Niekerk, 2011; Moi & Gjengedal, 2008; Moi, Vindenes, & Gjengedal, 2008). So who are these resilient people? They are people who can return rapidly to a previous state following trauma and who appear invulnerable to negative life
events (Holaday & McPhearson, 1997), or achieve successful adaptation to the traumatic effects (McAllister & McKinnon, 2009).

Health education practitioners have a responsibility to develop, implement, and evaluate programming that serves to promote the health of communities (NCHEC, 2008), and burn survivors are a community that shares a continued need for support (Kleve & Robinson, 1999; Van Loey, Faber, & Taal, 2001). The findings of this study offer an opportunity to learn more about how burn survivors perceive their journey toward survival, recover, and burn-specific health through the words of survivors themselves. Resilience theory holds possibilities for providing a theoretical framework that may illustrate the psychosocial strengths and protective factors of burn survivors. The theoretical framework may then be utilized to design future supportive programming.

“Embracing resilience and resilience theory prompts professionals to search for individual strengths in clients and then to nurture them. Resilience based therapy is to wade through protective layers of intellectualism, denial, shadows, and anger to discover a client’s innate resilience or human spirit” (Richardson, 2002, p. 317).
CHAPTER THREE
METHODOLOGY

Current burn care research relies primarily on empirical methodologies. These methodologies are focused on deficits and barriers that are believed to interfere with burn survivors’ long-term burn-specific health/wellness outcomes and chances for positive quality of life. Numerous researchers have conducted studies reflecting aspects of adult burn treatment (Atiyeh, Gunn, & Hayek, 2005; Brigham, & McLaughlin, 1996; Falder, et al., 2009), coping patterns and strategies (Kildal, Willebrand, Andersson, Gerdin, & Ekselius, 2005; Willebrand, Andersson, Kildal, & Ekselius, 2002), adjustment (Kleve & Robinson, 1999; Wallace & Lees, 1988), adaptation (Dyster-Aas, Kildal, Willebrand, Gerdin, & Ekselius, 2004), and burn-specific health (Van Loey, Faber, & Taal, 2001; Willebrand, Andersson, Kildal, Gerdin, & Ekselius, 2006; Wikehult, 2008), attempting to quantify survivors’ long-term outcomes. There has been minimal attention given to the personal stories of adult burn survivors (Moi & Gjengedal, 2008) in the United States, and the strengths they attribute to their burn-specific health/wellness. By utilizing qualitative methodology, we have an opportunity to explore the personal, social, cultural, spiritual, vocational, and cognitive representations of the burn experience through subjective accounts given by the burn survivors themselves.

Past American researchers have attempted to explore the burn experience through limited theoretical frameworks, but have primarily portrayed burn-related quality of life and burn-specific health within the deficit-based medical model as opposed to utilizing a strengths perspective. Even within the post-traumatic growth model (PTG) (Rosenbach & Renneberg, 2008), researchers rest on the notion that individual growth identified within their study sample
is extrinsic to the burned individual and secondary to burn injuries. Utilizing a phenomenological paradigm, I have described and interpreted the subjective, personal accounts associated with traumatic thermal burn injuries by exploring the stories of burn survivors. By focusing on the intrinsic and extrinsic assets that protect and support young and middle adult burn survivors through survival, recovery, and burn-specific health/wellness, there is the opportunity to further understand their experiences and insights. We may learn how survivors make meaning of their burn-related experiences, and then transform those experiential meanings into their personal life stories as both individuals and as a collective group. The results of this study may provide support for the use of a theoretical framework that best describes data obtained. The value of finding an appropriate theoretical model is that it may then be utilized for future health/wellness programming to support and build on those innate strengths that protect and support burn-specific health/wellness, adaptation, and quality of life for other burn survivors.

Purpose of the Study

The purpose of this study was to explore the psychological, emotional, spiritual, environmental, social, and vocational experiences of survival and recovery from the phenomenon of traumatic thermal burn injury and how survivors make meaning for these experiences within their life stories. Through their words we may gain an understanding of how they navigate their journey toward survival, recovery, and health/wellness following major thermal burn injury and the factors they attribute to their current health. In addition, this study explored how survivors’ home communities may impact long-term health outcomes and quality of life.
Research Questions

1. What is the burn experience for young and middle adults living in the Midwestern United States?

2. How do young and middle adult burn survivors living in the Midwestern U.S. make meaning for their major burn-related recovery and health?

3. How do structural networks/communities of young and middle adult burn survivors impact their burn-related recovery, health/wellness, and quality of life?

Research Design

This qualitative study is based on research questions that seek how (Moustakas, 1994) study participants experience major burn injury, navigate the processes of survival and recovery, and how they pursue optimal burn-specific health/wellness, adaptation, and quality of life following burn injuries. Positive burn-specific health/wellness may be defined as functional capabilities that support productive activities and having the psychosocial capacity to meet one’s chosen role in society (Falder, et al. 2009). The focus of qualitative research is based on constructivism, which means the researcher’s analytical interest is directed toward the meaning the phenomenon has for the person who has experienced it (Merriam, 2009). “Data for qualitative analysis is typically obtained through fieldwork, at which time the researcher immerses him/herself in the situation or group of interest, often as participant-observer, speaking directly with participants about their experiences relating to the research questions” (Patton, 2002, p. 4). Qualitative data has been found to be “highly” useful when research is intended to “unravel complicated and slowly evolving events” (Higgins & Mansell, 2008, p. 311). This perspective offers the researcher an opportunity to investigate how individuals construct their realities, in concert with their social world (Merriam, 2009). Moustakas (1994) contended, “The
deepest currents of meaning take place within the individual, through one’s senses, perceptions, beliefs and judgments” (p. 18).

My goal within this research was to depict how participants experience major thermal burn injuries through qualitative data collection and interpretation. This process requires a researcher to continually return to the “essence” of the burn experience to uncover its inner meaning (Merriam, 2009, p. 26). Through phenomenological investigation, this study has focused not specifically on the burn injury itself, but how it was experienced (Creswell, 2007) by participants, with particular focus on the recovery process as it occurs within survivors’ communities.

Phenomenological research, an approach within qualitative design, is grounded in the philosophical works of Edmund Husserl, with a primary focus on discovery and interpretation of human experiences in the natural environment (Merriam, 2009). It rests on the belief that “description” of how an experience is understood rather than “explanation” of why, providing the most useful data to identify and describe the essential elements of the lived experience (Churchill & Wertz, p. 245). The purpose behind phenomenology is to illuminate how people find meaning for experience/events. Moutstakas (1994) believed data interpretation should provide deep descriptions of general and universal meanings, or the essence of the experience of interest. Within these interviewer/interviewee interactions, it’s important for the researcher to have an “intuitive” connection with study participants, requiring the researcher to possess some knowledge or experience with the phenomenon under investigation (Churchill & Wertz, 2001, p. 251). My own knowledge and burn-related history provides that connection with participants. Unlike quantitative research which makes every attempt to remove the “footprint” of the
researcher from research findings, phenomenology relies on reflexive interpretation of data (Patton, 2002), embracing the insights of the researcher rather than attempting to neutralize them.

For these reasons, I made every effort to continuously reflect on my own burn-related experiences throughout the study process, addressing my feelings and thoughts about my personal experiences that may have impacted data interpretation (Moustakas, 1994). I attempted to bracket (Merriam, 2009) my own burn-related experiences so as to limit undue influence on data. By documenting my personal thoughts and perceptions throughout this research process within my reflexivity journal, I was able to share with the reader how those thoughts could have influenced my data interpretation.

Qualitative methods are often regarded with skepticism by the medical community (Malterud, 2001) and are minimally represented within burn care literature. Through the findings of this phenomenological study, there is an opportunity to deepen our understanding of the unique nature of burn recovery by exploring the young and middle adult survivors’ own stories, provided in their own words (Moi, Vindenes, & Gjengedal, 2008). With increased understanding of the factors participants believe contribute to their current burn-specific health/wellness, it may be possible to inspire those resilient strengths with other burn patients to promote more positive long-term burn-specific outcomes.

Pilot study

A pilot study for this research was conducted in the winter of 2011 as an effort for me to rehearse qualitative methods. Additionally, I hoped to discover a theoretical framework that might reflect successful long-term outcomes of those burn survivors who volunteered to be interviewed for the study. The pilot study utilized phenomenological, qualitative methodology. After receiving approval from SIUC’s Office for Special Projects, I made contact with the leader
of the burn support group associated with a regional burn center. I asked for permission to attend their monthly meeting and discuss my research interest. I attended the November support group meeting where I was afforded participant-observer status. At the end of the meeting I explained the purpose of my research to the group, and four survivor group attendees volunteered to participate in the study.

The initial research question for the pilot study was focused on how protective factors impact recovery outcomes for adult burn trauma survivors. This simplistic research question provided a foundation to further develop my current research questions. It also lead to more developed interview questions that uncover how participants perceive their burn-specific experiences, their health/wellness outcomes, and the factors they relate as being important to their recovery status. This shift away from the “what” and to the “how” of the burn injury experience was necessary as I learned more about the nuances of phenomenological research, and the importance of remaining neutral within data interpretation.

After interviewing pilot study participants, I was reminded of my experiences in Rochester where those who were living in or exposed to smaller communities with structurally supportive characteristics reported higher levels of adaptation and self-esteem. I also reflected on the adolescents I had met at burn camp who were from small, agricultural communities around southern Illinois who reported minimal social stigma regarding their burn scars. I reflected on my own experiences prior to moving from Michigan to a suburb of Chicago at age eleven and how the change in environment impacted my sense of self. It is for this reason I’ve decided to explore community protective factors that may contribute to participants’ adaptation, burn-specific health/wellness, and quality of life.
Pilot study participants included four adults. Male participants in the sample were 24 and 50 years of age, with TBSA thermal burns of 64 percent and 75 percent respectively. Females within the sample were 32 and 62 years of age with TBSA thermal burns of 14 percent and 76 percent respectively. Length of time since burn injuries ranged from 3 years to 54 years. Three of the participants were gainfully employed at the time of the study interviews and one was retired following a full career. All four burn survivors experienced burns that impaired joint function and none of the participants had facial burns. We met in a mutually acceptable location where we reviewed the interview process and IRB consent forms were signed. One individual, semi-structured audio recorded interview was conducted with each of the four participants by me. Each interview lasted approximately one hour. Interviews were later transcribed verbatim, and checked for content accuracy by each participant. Following member checking, line-by-line coding was conducted, and categories and themes were identified within data.

Categories and themes identified reflected examples of resilient protective factors of spirituality, social support, optimism, and plans for the future as important supportive factors/assets within pilot study participants’ journey toward survival, rehabilitation, and optimal burn-related health following their burn injuries. Findings from the pilot study support the belief that resilient protective factors influence positive health-related outcomes as found within resilience theory (Richardson, 2002).

Setting for the Study

After receiving SIUC’s Office of Special Projects and Springfield Committee for Research Involving Human Subjects (SCRIHS) (SIUSOM) approval, initial data collection for the primary study began by shadowing burn care providers at SIU School of Medicine (SIUSSOM)/Memorial Medical Center (MMC) burn unit for three days. This burn center is a
ten bed intensive-care unit serving approximately 200 burn patients per year from the primarily rural counties that make up central/southern Illinois and was chosen based on its association with Southern Illinois University at Carbondale (SIUC). After making contact with the burn unit Director’s office and then speaking with the Director of Plastic Surgery by telephone regarding my research interest, he agreed to participate in the research project by sitting on my doctoral committee and to act as gatekeeper for his unit. He also attempted to coordinate access to the eight bed University of Chicago (UoC) burn unit directed by a colleague. My gatekeeper helped coordinate my access to the burn unit at Memorial Medical Center, introducing me to unit staff. Unfortunately, I was unable to coordinate access to the burn unit at UoC due to complications and restrictions by their human subjects committee who considered all past patients vulnerable. After numerous e-mails and phone calls, I eventually lost contact with the Burn Unit Director.

While shadowing burn care providers on Memorial Medical Center’s burn unit, I hoped to gain some insights as to what my participants’ initial experience on the burn unit was like by watching the activities on the unit. I wanted to talk with providers about general patient progress while in the critical phase of treatment, possibly filling in some of the gaps of participant stories during periods when they were not conscious of their circumstances or surroundings. Through observation, I was able to gain greater understanding of how the critical phase of treatment, before and after survival of the patient has been established. I wanted to see patients and their significant others who were waiting for a positive prognosis, and how the stress of hospitalization impacts long-term health/wellness outcomes (Franulic, Gonzalez, Trucco, & Vallejos, 1996). In addition, by shadowing providers, I was given the opportunity to learn more about current treatment modalities to support the physical and psychosocial health of burn
patients. These treatment experiences are believed to leave a lasting impression on burn patients, ultimately impacting long-term health outcomes.

Following my clinical observations, I made contact with prospective participant burn survivors and significant others. I scheduled appointments to meet with each of the participants at a location of their choice. I also made arrangements for the use of the conference room adjacent to the burn unit through the nurse manager. My hope was that by meeting the participants within the hospital campus, the location would provide a safe atmosphere for participants as well as for me. During the initial portion of the interviews, I reviewed both SIUC’s and SIUSOM’s IRB forms and secured participant signatures on both institutions’ informed consent forms (Appendix C & E), and the release for audio recording/approval for quotation forms (Appendix D). I reviewed interview protocol and the voluntary nature of research participation prior to asking any of the interview questions.

Participants

The participants in this study were a non-probability, purposive sample recruited from the annual Burn Survivor Recognition dinner associated with MMC, personal recruitment by a participant, and from one of two patient mailing lists provided by the MMC nurse manager. Eight burn survivors and four significant others who participants identified as important to their personal survival and recovery were recruited for interviews. While it only meets the minimum number of participants I had hoped for, this number is reflective of current phenomenological literature reflecting sample groups between six (Lau & van Niekerk, 2011) and fifteen (Ploughman, Austin, Murdoch, Kearney, Fisk, Godwin, & Steffani, 2012) as providing adequate data for analysis. Data gathered from clinical observations from the unit were recorded in my field log.
Burned participants have not been treated on the burn unit within the previous year to allow for a period of “healing” and reflection following burn injuries. This period for healing and reflection is consistent with that required by the “Survivors Offering Assistance in Recovery” Program (SOAR) program for participation as a peer supporter (Personal communication with Sheila, Phoenix Society for Burn Survivors, Inc., 8/27/12) as well as the period identified by researchers as critical for patients’ ability to reflect on their suffering (Morse & Carter, 1996). To be considered for the study, participants had to be between 24 and 65 years of age, have sustained a major burn injury with ≥ 20 percent TBSA burns that include deep partial and full thickness burns to the face, hands, feet, or joints, and a minimum of 14 days of inpatient care. This TBSA and days of inpatient care criteria meet the definition for major burn injury requiring specialized burn care (ABA, 2009). The criterion is also reported to represent a threshold for decreased “general health” and perceived quality of life for burn survivors (Fauerbach, Lezotte, Hills, Gromes, Kowalske, de Lateur, Goodwin, Blakeney, Herndon, Wiechman, Engrav, & Patterson, 2005, p. 22).

Burn support groups are as unique as the catchment areas they serve. Each of the two burn units I hoped would participate within this primary study once held their burn support meetings within the hospital complex were the burn centers are located, allowing access for to patients being treated on the burn unit and their families, as well as burn survivors and their families living in the surrounding communities. Alan Bresslau, founder of the Phoenix Society for Burn Survivors, once told me that support groups are like a bus, people get on them when they need them, and get off when they don’t feel the need. Some people attend support group meetings often, and others only sporadically, but the groups were open to anyone who cared to attend. SIUSOM allowed experienced burn survivors to visit burn patients on the unit however
the limitations in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) limited access to patients by burn survivor visitors who are no longer allowed on the unit. The support groups associated with the two burn units are currently inactive with no plans to reinstate.

After having an opportunity to shadow burn care providers at SIUSOM/MMC’s burn unit for at two and a half days, and half a day in the burn clinic, I began to recruit burn survivors who had volunteered at the burn survivors’ dinner. I was informed that University of Chicago’s eight bed burn unit had hosted a monthly support group meetings that was affiliated with the Phoenix Society for Burn Survivors Inc.’s SOAR program (www.phoenix-society.org). The SOAR program is an organizational support “package” designed by burn survivors and burn care professionals to support systematic programming and leadership of burn support groups and marketed throughout North America (www.phoenix-society.org). The director of the unit proved unable to provide access to the UoC unit and discontinued his e-mail contact with me, ending my hopes of including UoC’s patient base within my participant pool despite support from my gatekeeper.

I was able to personally recruit six study participants who were treated at SIUSOM’s Annual Burn Survivor Recognition Dinner which was held in an off-campus location on November 14, 2012. The dinner is typically attended by past patients, their families, and burn care providers (Personal communication, Meyer-Cox, 8/27/2012). The unit psychologist informed me the dinner is typically attended by 50 to 75 people, including about 20 burn survivors, their family members, and burn unit staff.

People are greatly influenced by developmental processes, both biologically and cognitively. Social cognitive theory identifies many of the determinants influencing behavior
that are impacted by the point in the lifespan in which they occur (Bandura, 1989). While some behavioral factors may be physiological, others may be customary, with cultural influences rooted within familial, educational, and/or institutional systems (Bandura, 1989). Factors influencing behavior may come from unexpected and unpredictable occurrences, such as major thermal burn injury. It is believed that within psychosocial development, each person must overcome specific, age-related crises before they can successfully advance beyond a given developmental stage (Erikson, 1998). Early and middle adults, age 24 to 65, are believed to experience unique developmental challenges that can be interrupted or derailed by major thermal burn injury and subsequent rehabilitation.

Bandura (1989) believed that many of the determinants that influence behavior are impacted by the point in the lifespan in which they occur. Participants will be adults between 24 years of age to 65 years of age, reflecting the age range of young to middle adults (Erikson, 1998). This age range was chosen based on the unique recovery challenges reflected within two of Erikson’s (1968) eight stages of development (Vogel-Scribilia, McNulty, Baxter, Miller, Dine, & Frese, 2009). Erikson (1968) believed that humans progress through predictable patterns of psychosocial development, which he characterizes as crises (Erikson, 1998). The psychosocial crisis of young adult development (ages 22-32) is referred to as “intimacy vs. isolation,” highlighting the importance of developing and maintaining intimate relationships (Hutchison, 2010, p. 276; Vogel-Scribilia, et al., 2009, p. 406). For middle adults (ages 33-62), the psychosocial crisis is believed to be “generativity vs. stagnation” (Hutchison, 2010, p. 315; Vogel-Scribilia, et al., 2009, p. 406), indicating the importance for middle adults to possess the ability to pursue activities that will benefit future generations, establish and work toward goals, and feel productive within their social environments (Hutchison, 2010; Vogel-Scibilia, et al.,
Due to the limited availability of potential participants, I chose to expand the age parameters by three years for older adults to include additional participants that would have been excluded otherwise. This made sense to me as people remain in the workforce much longer today than in previous decades.

By including early and middle adults in the sample pool, I anticipated data would provide evidence for how study participants experience their developmental milestones in relationship to their burn injuries. Data also reflected participants’ engagement in meaningful employment following their injuries, believed to be instrumental to adjustment and greater quality of life. I believe it is important not just to recognize when the burn injury occurred, but also at what point in psychosocial development the story of the experience is shared which is why I included Jake and his wife. The psychosocial stage of development in which the participant is speaking is impacted by their current developmental needs. Although Jake was 78 at the time of his interview, he was burned at age 61 and his burn injuries interrupted his employment history permanently.

Participant Recruitment

My experiences with both adult burn survivors attending support group meetings and adolescent who attend burn camp have left me with the impression that those who return from regional burn centers to smaller, densely dispersed communities, enjoy a greater level of social support, and experience greater levels of social acceptance and self-esteem. For these reasons, I had intended to include burn survivors and their significant others from both University of Chicago and Southern Illinois University School of Medicine. These two burn centers serve very different catchment areas with SIUSOM/MMC serving a primarily rural catchment area of and UoC which serves a primarily urban catchment area. Unfortunately, I was not able to
include burn survivors who were treated at UoC due to issues with their human subjects committee’s approval of the study.

Once at the Annual Burn Survivors’ Dinner, my gatekeeper was kind enough to introduce me to the attendees at the dinner where I was able to speak about my research interests. I reviewed the purpose of my research and attempted to recruit burn survivor volunteers for research participation by making a verbal request, a process that was successful for my pilot study. At the close of the dinner celebrations, six attendees who were interested in participation approached me and provided their contact information. I informed them of the time frame which would include my clinical observations and that it might be as long as a month before the interviews.

Once burn survivors had agreed to participate, I requested that each participating survivor solicit one significant other for participation in the study, although this wasn’t a criteria for participation. Significant others could be important friends or family who provided important social support during the survival and rehabilitation phase of burn treatment. This inclusion was important as social support is found to be positively correlated with psychosocial adjustment to burn injuries (Wallis, et al., 2006). In addition, securing data relative to the perspective of someone who was present during the critical phase of burn treatment provides an opportunity for triangulation of data (Merriam, 2009; Patton, 2002). A total of four significant others volunteered including one mother and three wives. Interview questions (Appendix G) asked of significant others were focused on their perspective of the burn survivors’ experiences.

I was able to recruit six participants at the burn survivor dinner. I contacted participant volunteers by telephone and dates for interviews were scheduled. One additional participant was recruited by Jake. Recognizing the need for at least one more participant to at least meet my
proposed minimum participant number of eight, I made a request for and was provided with two patient mailing lists by the MMC nurse manager. The first list contained fifteen names and addresses for discharged burn unit patients from MMC’s burn unit in the years 2010 to 2011 who met the parameters for this study. I sent recruitment letters to all of the names on the mailing list through the U.S. Postal Service. Within several days I received two e-mails from recipients of the recruitment letters; one e-mail from the daughter of a deceased burn patient and the other from the father of deceased burn patient. At first I was embarrassed that I had intruded on the families’ lives, having never considered that it might happen. However as I read on, both e-mails offered kind words of encouragement for my research in hopes that it might help future burn patients. In return, I sent e-mails to each of the surviving family members offering my gratitude for their encouraging words and condolences for their loss. The following week, I sent an additional eighteen recruitment letters from the 2008 to 2009 patient list I had received from the nurse manager. Four envelopes were returned to me as undeliverable. Within about one week of mailing the second group of letters, I received a telephone call from Sid who had received a recruitment letter in the mail and wanted to participate in the study.

Interviews

Appointments with participants were made by telephone. I met with participants at various locations in the region for face-to-face audio recorded interviews utilizing a semi-structured interview script as a framework to explore and elucidate participant responses intended to answer my research questions. I also had the opportunity to use probing questions that would prompt participants to provide additional information to support initial responses. Interview questions were adapted in part from my pilot study. The script included questions I believed would elicit information about participants’ health within all six dimensions. Since
organizing the interview script for my pilot study, I had delved more deeply into supporting
literature, and experienced some of the discomfort that goes along with ill prepared questions.
Questions included within the interview scripts (Appendices F & G) were then adapted from
both my pilot study and those reported by Holaday & McPhearson’s (1997) research on
resilience and severe burns. The balance of the interview questions were based on my
knowledge of and therapeutic experience with intentional interviewing. My tenure as a social
worker has provided me with some insight as to asking intentional questions so that interviewee
responses will provide the information being sought (Ivey, Ivey, & Zalaquett, 2007). Study
questions will not be peer reviewed by burn survivors, but rather by only my committee
members.

Before the audio recorders were turned on at each interview, participants and I chatted for
a while, talking about the events of their day or what they would be doing after the interview/s.
At the opening of each audio-recorded interview, I reviewed all informed consent documents,
secured their signatures on the informed consent papers for both SIUC and SIUSOM, and
explained how the interview would be conducted. Audio-recorded interviews with participants
were approximately forty minutes in length and continued until participants felt they had
completely answered the interview questions and addressed the information they hoped to
convey. I immediately followed participant interviews with a thirty to forty minute interview
with their “significant other” if one was present. Participants and significant others were
interviewed only one time. Questions asked of the significant others were focused on the
experiences of the participant. I had an opportunity to engage participants at the close of each
session to member check my verbal summary for accuracy relative to my understanding of the
context of their responses. At first I was apprehensive about interviewing both the participant
and their significant other while they sat together at the table, not being sure if they might be more forthcoming if not in the presence of the other. I soon found that the couples provided important support for each other, sometimes filling in gaps in memory, providing an empathetic look or a touch to the arm when the interviewee was struggling with a particularly emotional response.

By the close of the interviews, I had met with eight burn survivors and four significant others over the course of four weeks. Following verbatim transcription of interviews, participants were asked to member check of their transcript, which I sent to them by email or the U.S. Postal Service. Member checking is believed to support trustworthiness and credibility of data (Merriam, 2009). Once transcript accuracy was determined through member checking, data were analyzed, reflecting the importance of direct quotations from people about their experiences, opinions, feelings, knowledge, and detailed descriptions of behaviors and actions (Merriam, 2009) relative to their burn injury. There was no compensation for participation in this study. I took great care to assure each participant that they could discontinue the interview at any time. Participants’ names and demographic information has been kept confidential within this paper by providing pseudonym. All transcripts, field notes, and my reflexive journal were considered for data analysis, as I searched for categories and themes that reflected shared meaning within the data.

To support data obtained through interviews, I maintained a field log to document my observations while shadowing burn care providers and a reflexivity journal to document my thoughts and feelings throughout the investigative process (Creswell, 2007). As the sole interviewer of participants, I had the opportunity to be immediately respectful, empathetic, neutral, and fully mindful of the sensitive nature of my questions (Patton, 2002), observing and
documenting non-verbal behaviors (Merriam, 2009) within my field log. Additionally, I was in a position to encourage participants to delve into their burn-related experiences and feelings, prompting greater depth within their story-telling, sometimes surprising participants by asking questions that were not included within their burn “story” that was typically shared.

Data Collection

In-depth, individual interviews were conducting using semi-structured interview scripts (Appendices F & G) as a framework for interviews. The semi-structured scripts allowed for flexibility and spontaneity within interviews. Interviews were conducted in the conference room adjacent to the burn unit as well as three separate restaurants close to the towns in which the participants reside. No additional follow-up interviews were requested by the study participants. Current literature acknowledges the value of systematic collection and interpretation of textual data derived from interviews and observations as an accepted standard of qualitative research (Malterud, 2001).

Data collection for qualitative research is subjective and entails the researcher positioning her/himself as a visible, direct observer, interviewing participants regarding the experiences of interest (Merriam, 2009). As a researcher, I felt it important to consider my own experiences and biases that might influence the interpretation of data. As I navigated my “metapositions” (Malterud, 2009, p. 284) of survivor and researcher within the research process, the influence of my own burn injury posed a benefit as well as a liability to this study. This methodological point is the foundation for the researcher’s commitment to reflexivity (Malterud, 2009). Within this research project I wore a number of hats. Within this study I was a researcher, burn survivor, parent, visitor, and the voice for those who volunteered to share their burn-related stories. “The illusion of denying the human touch is countered by establishing an agenda for
assessment of subjectivity” (Malterud, 2009, p. 484). Living the majority of my life as a burn survivor has provided me with many insights into the kind of challenges that often accompany burn-related disfigurement, and a deeper understanding of those challenges than could be possible for a complete outsider.

Data Analysis

Following verbatim transcription of interviews, I mailed transcripts and self-addressed, stamped envelopes to each participant for their review, asking them to respond as to the accuracy of the transcripts. Six of the participants responded to my letters indicating the transcripts were accurate. Transcripts were coded line by line, identifying dominant categories and recurring themes within data, and then analyzing data for shared meaning among the sample group (Merriam, 2009). I was searching for similarities within and among participant stories (Patton, 2002). “The human scientist determines the underlying structures of an experience by interpreting the original descriptions in the situation in which the experience occurs” (Moustakas, 1994, p. 13). My own burn-related experiences had to be recognized and bracketed (set aside) to the best of my ability so as not to alter the contextual meaning intended by the interviewees. Analysis of my field log provided additional supportive data to research findings, indicating interviewee non-verbal behaviors and environmental details. As the sole investigator of this research, it was very important to consider my own burn injury, burn support experiences, and work history as a mental health professional when collecting and interpreting data, making every effort to be reflexive of my personal experiences or perceptions that could influence study findings. It was for this reason, I chose to include a reflexivity statement within the preface of this dissertation and interspersed throughout the findings as it may have been relevant. In an effort to minimize the limitations of being the sole researcher, and the risks of data being unduly
influenced by my personal experiences and subjectivities, data analysis will be reviewed by a
colleague, Denise Demers, a doctoral candidate within my department.

I was able to utilize multiple data sources, including transcripts from face to face
interviews, observations of day to day activities of the SIUSOM/MMC burn unit, non-verbal
observations of participants and significant others in my field notes, as well as findings from my
pilot study to support triangulation of data (Creswell, 2007; Merriam, 2009). I also employed
member checking (Creswell, 2007; Merriam, 2009) with participants at the close of each
interview session to confirm my accurate understanding of data, and again following verbatim
interview transcription that I sent to participants by e-mail or the U.S. Postal Service. I made
every effort to pursue maximum depth within the stories provided by participants through
“adequate engagement” (Merriam, 2009, p. 219) as we explored their burn-related experiences,
beliefs, perceptions, and feelings, making every effort not to interrupt, allowing participants to
continue with their stories until they felt they had fully answered the questions.

Validity

Credibility

Credibility, or internal validity, is reflective of the rigor in which the researcher pursues
data, and how accurately the research findings reflect the true context of the story as delivered by
the story-teller (Patton, 2002). “Because human beings are the primary instrument of data
collection and analysis in qualitative research, interpretations of reality are accessed directly
through their observations and interviews” (Merriam, 2009, p. 214). To protect credibility
within data, I included a preface to this dissertation to reflect my experiences with and as a burn
survivor. I also made every effort to recruit the inclusion of significant others to provide
supporting information about the participants and their burn-related experiences. During each
participant interview and at the close, I summarized my understanding of participants’ and/or significant others’ stories with the interviewee to check for accuracy. Following verbatim transcription of each interview with participants and significant others (if one accompanied a participant), I mailed a copy of the transcript to each participant and significant other through the U.S. Postal Service for review. In the mailing with the transcripts, I included a letter requesting their written input on the accuracy of the transcripts and a self-addressed stamped envelope to encourage their response. Of the eight participants, I received four return letters and one e-mail indicating those participants agreed the transcripts accurately reflected their interviews. Lastly, I have attempted to include detailed descriptions within data analysis to support my research findings.

Trustworthiness

Trustworthiness within qualitative research is focused on the ethics of the researcher and if the researcher has been sufficiently rigorous in their study design (Merriam, 2009). I utilized multiple data sources to support my findings, including verbatim transcripts, member checking with participants at the close of interviews as well as after transcription, my reflexivity journal, findings from my pilot study, and field notes reflecting my observations of the activities on the burn unit, discourse with providers, and observations of non-verbal behavior during participant and significant other interviews for triangulation purposes.

Dependability/Consistency

Unlike quantitative research, qualitative methods are difficult to replicate as they are based on the unique realities of the participants being observed (Merriam, 2009). “…rather than demanding that outsiders get the same results, a researcher wishes outsiders to concur that, given the data collected, the results make sense—they are consistent and dependable” (Merriam, 2009,
Merriam (2009) observes that while it is difficult to replicate a qualitative study, what is encouraged is that the data collected provide consistent and dependable results. To support dependability and consistency within this study, my colleague Denise Demers has reviewed the transcripts and my categories for consistency in analysis.

**Transferability**

Malterud (2001) describes transferability as “The range and limitations for application of the study findings, beyond the context in which the study was done” (p. 484). I had hoped to access greater variation in sampling by recruiting participants from the University of Chicago’s burn center in addition to MMC however that was not possible. My sampling was based on all of the volunteers available that met or were close to meeting the parameters of the study that made themselves available for interviews. Participants were from varying locations around the catchment area for MMC and represented both rural and more heavily populated communities. The sample was predominantly male with only one female who volunteered to participate in this study and all participants were Caucasians. I have attempted to compensate for the minimal variation in my participant sample by providing the use of rich, detailed descriptions within the research findings which is believed to provide greater depth and transferability of data (Creswell, 2007). I have also utilized my own experiences as a burn survivor to augment the detail within the study. For these reasons, transferability outside of this rural catchment area may be limited.

**Summary**

The purpose of this study was to explore how young and middle adult men and women navigate survival, recovery and burn-specific health/wellness following major thermal burn injury. Through qualitative methodology, the results of this phenomenological study gives voice to survivors of major thermal burn injury, exploring individual and shared feelings,
understandings, and meanings (Moustakas, 1994) attached to participants’ burn-related experiences. In addition, I took great care to reflect on my own burn-related experiences and insights throughout the process of this research, contributing to the rigor of the study through reflexivity and triangulation. By acquiring data within a naturalistic rather than a controlled environment (Patton, 2002), the results of this primary study provide an opportunity for further understanding of how survivors make sense of their burn-related experiences, and then transform their experiences into their life stories as individuals, and through shared meaning as a group (Patton, 2002). Advancing the knowledge base of health educators regarding the needs of this growing population will provide a foundation on which to design, implement, and evaluate future supportive health education programming that may then improve long-term health outcomes for other burn survivors.
Purpose of the Study

The purpose of this study is to explore the psychological, emotional, spiritual, environmental, social, and vocational experiences of survival and recovery from the phenomenon of traumatic thermal burn injury and how survivors make meaning for these experiences within their life stories. Through their words we may gain an understanding of how participants navigate their journey toward survival, recovery, and health/wellness following major thermal burn injury and the factors they attribute to their current health. In addition, this study will explore how survivors’ home communities may impact long-term health outcomes and quality of life. Through data analysis, the themes that emerged within data included “How it Feels,” “Somehow, I’m Still the Same,” and “Yet, I’m Better.” These themes provide a window into recovery and health following major burn injury and how the participants of this study found meaning within the experiences and integrated the experiences into their life stories that are then shared with others.

This chapter presents a summary of study findings including a brief description of the volunteers who chose to participate in this study. I’ve provided pseudonyms in place of actual participant names to maintain their confidentiality. The categories and themes included within this chapter portray the lived experiences of eight burn survivors and their significant others who volunteered their time and emotional investment to increase our knowledge about how early and middle adults live with their burn injuries. In addition, this chapter includes answers to the three research questions which guided this study:
1. What is the burn experience for young and middle adults living in the Midwestern region of the United States?

2. How do young and middle adult burn survivors living in the Midwestern United States make meaning for their major burn-related recovery and health?

3. How do the structural networks/communities of young and middle adult burn survivors impact their burn-related recovery, health/wellness, and quality of life?

In the Beginning

My journey began after being invited by my gatekeeper, to attend the Annual Burn Survivor Recognition dinner sponsored by the burn unit at Memorial Medical Center (MMC) in Springfield. All of the patients who have been treated on the unit were invited to the banquet that was held in November of 2012. The banquet hall owned by the local firefighters was on a dark, remote road that ran around the northern perimeter of the lake in Springfield. After being lost for almost an hour and becoming frantic, I finally found the building and made my way into the large dining room filled with burn survivors, their family members, and burn unit staff as they finished their “cocktail hour” and moved toward their tables for dinner. The room felt very warm and friendly despite my agitation from being lost and my nervousness at being in a place where I knew almost no one. My gatekeeper welcomed me and I sat down at a table with several burn survivors and their families who were quick to share the abridged version of their burn story.

The burn unit Director had told me that every year they have a speaker at the banquet and that year Alyssa, a Physicians’ Assistant, was the keynote speaker. She spoke lovingly of her time working with patients on the MMC burn unit and how she felt the experience had significantly impacted her young adult life. Her story was heartwarming as she spoke, drawing
tears from her as well as the groups sitting at the tables. When she was done speaking, I was called up to the front of the room by my gatekeeper, handed a microphone and asked to talk a bit about my own burn recovery and my hopes to recruit participants for this study. At the close of the dinner my gatekeeper introduced to a number of burn survivors who expressed their interest in participating in the study.

Six dinner attendees volunteered to participate and provided me with their contact information. Of those six volunteers, four had significant others who also were willing to participate in the study. Although I had approval from SIUC’s Office of Special Projects at the time of the dinner, obtaining Springfield Committee for Research Involving Human Subjects (SCRIHS) approval from SIU School of Medicine (SIUSOM) proved to be much more rigorous, requiring an additional month of revisions to satisfy their concerns about study procedure and participant safety. Once their approval was secured, I moved forward to begin my clinical observations and establish contact with the participant volunteers.

Obtaining clearance to observe at Memorial Medical Center (MMC) also proved to be more challenging than I had expected. First, it was necessary to obtain a signature from the chair of my department and the Chancellor of the university to amend an already existing agreement between the SIUC and MMC to include the Health Education and Recreation department. Once the agreement was in place, I was required to complete MMC’s “KnowledgeNet” education and safety modules prior to being allowed on the burn unit, much like nursing and medical students who are preparing for their practicum at the hospital. I completed twenty on-line modules to prepare me for being in the MMC environment.
Memorial Medical Center

MMC is a Level I trauma center and for this reason, patients are most often transferred to the burn unit from area hospitals when the emergency room physicians have deemed the patient’s burns to be beyond their treatment capabilities. Even though there is a protocol for when to send a patient on to MMC, Tracy, a burn unit secretary, told me that the transfer often begins with a phone call from an ER doctor who isn’t sure what to do. When the decision is made that the patient’s medical needs could be met best at MMC, the transfer to the regional medical center is made by helicopter or ambulance, whichever is believed to be the most expedient.

I was given a hospital name badge and a parking pass on the first day of my clinical observations and told by the nurse manager that I had been cleared to move freely around the hospital. I wanted to begin my data collection by spending time on the burn unit as this is where the transition from victim of major burn injury to burn survivor began for my participants. This is the place where they started the healing process and was likely the place where their loved ones first saw them following the burn event. I wanted to make sure my recollections of a burn unit were accurate. I wanted to see what new treatments were available and what the nurses had to say about burn care. I hoped to observe the physicians’ involvement with patient care. I also wanted to observe contact the medical staff had with visitors who might have been waiting for a positive word about their loved one’s condition.

What I found was that the burn unit was truly where recovery began for my participants. For two and a half days, I observed the routine of burn care at MMC. I watched burn unit staff as they readied a room for a patient’s arrival [which takes upwards of three hours to disinfect and sanitize] and watched as the patient arrived. It takes several hours to settle a burn patient into
their room while medical staff assess wounds and organize a treatment plan before the family is allowed to join them.

For visitors, the way to the burn unit takes a somewhat different path than for the patient. The burn unit at MMC is on the fifth floor of the “Garden” section of the hospital. When stepping off the elevator, I was struck by the emptiness of the long empty hallway lit by bright white, overhead florescent bulbs and thick, glossy wax on the floor that made it feel tacky and caught the soles of my shoes. Half-way down the hall and to the right was a door leading into a small entryway that provided a “buffer” zone before entering the burn unit. Passing through the second door the changes in the environment became obvious as providers moved about, smiling and talking with cop-workers, patients, and visitors. There were signs posted informing visitors they must wash their hands on entering to avoid risk of infection, a practice that is stressed throughout MMC. Inside the door on the right, there was a Christmas tree with decorations that felt like a small reminder of the upcoming holiday that might have slipped the minds of the patients and their visitors when compared to the family crisis they were going through. The unit consisted of ten, single occupancy rooms that formed a glass “L” around the long desk that is the nurses’ station, allowing nursing staff to see into patients’ rooms unless the curtains were pulled closed.

Attached to the door frames of patient rooms were hand sanitizer pumps that were accessed regularly by burn care providers and visitors who entered and exited the patient rooms, and sometimes used by anyone who just happened to walk by. Next to patient room doors stood tall stainless steel carts filled with paper gowns, surgical masks, latex gloves in three sizes, and head covers to be used by anyone who entered a patient room, also in an effort to decrease the risk of spreading infection to either the patient or the visitor. An adjacent room to the open area
around the nurses’ station held a long row of large hydrotherapy tubs with curtains hanging between each one to offer patients a minimum of privacy. I intentionally sat alone in the room for about half an hour to test my nerve because that “tub room” seemed more intimidating to me than any patient room I had seen. Thankfully, I survived the experience of being alone in the room with the hydrotherapy tubs, retiring my childhood memory of being the unhappy patient in the whirling, hot water.

Four rooms were occupied by burn patients at the time of my observations; the other six rooms were temporary homes for medical intensive care patients. The unit was brightly lit with soft Christmas music playing, only interrupted by quiet conversation and an occasional beep from the many patient monitors located behind the nurses’ station desk. While sitting behind the long desk, I watched the nurses as they monitored patients’ conditions and provided care. The nurses answered all of my questions and even explained some of the more current life-saving procedures such as the Parkland Formula used to determine the necessary fluid volumes needed for resuscitation of a burn patient, which was made a little more precarious for the man in room 8 with hypertension whose diuretic prescription made the equation a bit more challenging.

I watched the first and second year surgical residents who reminded me of tourists on the unit as they spoke to patients with loud, slow words while they conducted their rounds. They put on their paper gowns and surgical masks, and snapped on new latex gloves before entering each room to meet with their patient: “HEL-LO MIS-TER JOHN-SON.” The residents then quietly talked between themselves as they removed their paper gowns, masks, and latex gloves, popping them in the trash as they left the room. There was a smooth rhythm about the unit as medical staff made their way in and out of patient rooms, putting on paper gowns, masks, and latex gloves as they entered a patient room, and stripping them off as they exited. Sue, a nurse who
had been working on the burn unit for more than thirty years told me that the rhythm was because the doctors and nurses had worked together for a number of years and were very compatible. While standing or sitting off to the side to stay out of the way, I was able to get a glimpse of what those early days on the burn unit must have been like for my participants, their families, and their friends.

While spending the two and a half days on the burn unit was intended to be an opportunity to observe what the initial experiences of burn treatment might have been for my participants, it was also intended to check my reflexivity for being around burn injuries before I met with my participants for interviews. My only distress while on the burn unit was when watching a man who was asked to squeeze a bandaged hand into a fist. It made me cringe and reminded me of the intense pain experienced when having to move any burned part of the body which was necessary to facilitate future movement of the area.

I spent half a day at the MMC outpatient wound clinic that serves burn patients who are recently discharged from the unit and those living in the MMC catchment area requiring specialized care for their burns that do not require reconstruction. I was allowed in the patient examination room for the only patient of the day as the nurse practitioner and surgical resident cleaned the burn wound of a man who had been treated at an area hospital, not MMC. As they scrubbed the open burn on the man’s forearm to debride the necrotic and infected tissue, his wife looked at me with such pain in her eyes and all I could say to her was, “It gets better,” which seemed to somewhat appease her as she then turned her attention back to her husband to provide him with emotional support. These were likely the same kinds of experiences that my participants had when they were treated at MMC’s outpatient clinic.
Following my three day clinical observations at MMC, I contacted the survivors who had volunteered for participation at the Burn Survivors’ Recognition dinner in November. I was worried as it was already after Christmas by this time and I was concerned that some of the volunteers might have changed their minds or lost interest in the study. But after contacting volunteers by telephone all agreed to appointments to meet at various locations around the region that were most convenient for them. I was set to begin interviewing the burn survivors. Two additional appointments were set after Trooper was recruited by Jake, and Sid was recruited through my mailed recruitment requests.

Demographics

Of the eight burn survivors who volunteered to participate in this study, seven were men, and one a woman. Of the significant others who volunteered to participate, three were wives and one was a mother. The mean age of the participants at the time of interviewing was 54.38 years of age (range 37-78) and mean age of participants at the time of their burn injury was 42.38 (range 21-61). All eight participants were Caucasian. I hadn’t given any consideration as to race or gender of potential participants, given the original recruitment plan was to include a metropolitan area where I hoped to obtain a more varied participant sample. I was thrilled with the eight burn survivors who volunteered and met the criteria of > 20% TBSA burns and early and middle adulthood age parameters for participation. Of the eight participants, four were married at the time of their burn injuries, one married later in life, one was divorced, one never married, and one was involved in divorce proceedings at the time of the interview. Jake, Steve, and Matt had children at the time of their injuries, and Dan had children by marriage. The longest period of time since any of the participants’ burn injuries occurred was twenty-three years (Trooper) and the shortest period of time was just over one year (Steve). At the time of
their burn injuries and of the interviews, all of the participants resided in the central Illinois
catchment area for the Southern Illinois University School of Medicine/Memorial Medical
Center’s burn center (Table 1). Jake was older than the criteria set for this study however he was
only 61 at the time of his burn injury. His burns were work-related and I felt his story was
important to this study as it reflected how burn injuries on the job can reshape a person’s
employment status and life story.

Table 1

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Race</th>
<th>Marital Status</th>
<th>Age at time of injury</th>
<th>TBSA %</th>
<th>Cause of burn injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beth</td>
<td>37</td>
<td>Caucasian</td>
<td>Divorced</td>
<td>25</td>
<td>20</td>
<td>Scalding - in the home</td>
</tr>
<tr>
<td>Jake</td>
<td>78</td>
<td>Caucasian</td>
<td>Married</td>
<td>61</td>
<td>65</td>
<td>Flame - Natural gas explosion on the job</td>
</tr>
<tr>
<td>Steve</td>
<td>37</td>
<td>Caucasian</td>
<td>Married</td>
<td>36</td>
<td>40</td>
<td>Flame - gas explosion working on farm tractor</td>
</tr>
<tr>
<td>Matt</td>
<td>64</td>
<td>Caucasian</td>
<td>Married</td>
<td>50</td>
<td>33</td>
<td>Electrical arc - on the job</td>
</tr>
<tr>
<td>Dan</td>
<td>44</td>
<td>Caucasian</td>
<td>Married</td>
<td>21</td>
<td>36</td>
<td>Flame - gas explosion in the home garage</td>
</tr>
<tr>
<td>Sanders</td>
<td>62</td>
<td>Caucasian</td>
<td>Married</td>
<td>58</td>
<td>42</td>
<td>Scalding - in the home</td>
</tr>
<tr>
<td>Trooper</td>
<td>64</td>
<td>Caucasian</td>
<td>Single</td>
<td>42</td>
<td>94</td>
<td>Flame - gas explosion in the home</td>
</tr>
<tr>
<td>Sid</td>
<td>49</td>
<td>Caucasian</td>
<td>Divorcing</td>
<td>46</td>
<td>98</td>
<td>Flame - Oil field explosion on the job</td>
</tr>
</tbody>
</table>
Meeting the Participants

I’ve positioned the participants in the order they were interviewed with no thought to which story was more important or difficult than the next. They were all important, and I credit each participant’s bravery to meet with me, a total stranger who pried into one of the most profound experiences of their lives and asked probing questions about what it was like to survive a major burn injury as well as how they make the journey toward recovery.

Beth

My first interview was with Beth and her mother at a Steak & Shake during the lunch hour. I arrived early and chose a four-top table in the far corner of the dining room to offer as much privacy as possible as the loud Thursday lunch crowd converged on the tiny restaurant. Upon entering, Beth recognized me right away as we had sat together at the burn survivors’ dinner, and led her mother over to the table. Beth had chosen this location for the interview and she and her mother ordered their lunch as I readied the two audio recorders. First I interviewed Beth as her mother sat next to her and quietly ate her lunch. Beth answered my interview questions with great depth, softly sighing on several occasions but laughing about many of her experiences as she talked about her burn event and her journey toward recovery. She played with her food that arrived while we were talking, dabbing her French fries into the deep red catsup and taking long drinks of soda from a straw as she paused between sentences.

Beth was 37 years old at the time of the interview and was the only female in the group of participants. She sustained 20% TBSA burns in 2001 when scalding water was spilled on her feet. She was divorced however her burns were not a factor in the divorce that occurred years after her injuries. She giggled when she told me he had cheated on her with a friend, covering her mouth like a little girl and looking over to her mother who giggled along with her like they
shared a secret. Beth was a large woman who said that she had gained a lot of weight on the necessary high calorie diet while on the burn unit. Because of her injured feet, she said she hadn’t been able to drop the weight over the years that had passed since her hospitalization because of the pain associated with walking, and blamed the weight gain for her insulin-dependent Type II diabetes. Beth lived in her parents’ home located in one of the larger cities in central Illinois and brought her mother to the interview as her “significant other.”

It was obvious that the two women spent a lot of time together with Beth appearing somewhat dependent on her mom, looking over at her for support during the interview and to verify her memories of the events that preceded and followed her burn injuries. She had sustained first, second, and third degree burns to her feet and ankles, with burns running up her shins toward her knees that were complicated by an infection that set in before her health care providers made the decision to send her to MMC.

“…we were living in a trailer. My husband, now ex-husband, we were living in a trailer and um, the water heater didn’t work like it should so we had to boil water to take baths. Showers were almost out of the question…Um, so we were boiling water and he was in the tub and I carried a pan of boiling water to add to the bath water and um, we had told the landlord there was a weak spot in the floor of the bathroom as well and he didn’t do much about it. Uh, I hit the weak spot and ended up dropping the pan of water all over my feet. Um, I had socks and sandals on, um I didn’t uh have actual shoes on to cover my feet so (pause) it it instantly took my skin off. When I I took the socks off the skin came with it. Um, but I had (sigh) ooh, I had a big big pan of boiling water all down my feet.”
There is a protocol for transferring patients from outlying hospitals to the regional burn center in Springfield however burns can be deceiving, worsening over the following days as tissue dies and the risk of infection becomes more of a concern. Beth had been to two area hospitals for treatment before her primary care physician made the decision to send her to Springfield. Her mother informed me that she was very involved with Beth’s recovery, and brought both Beth and her husband to live at her home while Beth healed. Beth described her quality of life and health at the time of the interview as poor with recurring bouts of depression, panic, and two separate episodes of cancer that were found on her kidney and gallbladder. She said she has also had issues with her thyroid. Her chief concerns about her burns were the pain and embarrassment associated with her scarred and grafted feet, making it difficult to walk at times and even harder to find shoes that fit comfortably. Beth laughed openly throughout the interview. She even laughed when the story line centered on more serious subjects like when she spoke of her hospitalization experiences, her subsequent health issues, and her limited social network.

After completing my interview with Beth, I interviewed her mother who had volunteered as a “significant other.” She answered questions about her daughter’s burn experiences while Beth sat at the table next to her mom, finally taking the opportunity to eat her lunch. The interview with her mother was unremarkable, and I felt more comfortable with my interview questions as I was able to gather the kind of depth and definition from both Beth and her mom that I had hoped for.

Jake

The second participant interview was the following afternoon with Jake and his wife, conducted at a Monical’s Pizza restaurant. This location was chosen by the participant and his
wife as it was a common lunchtime destination for them. I found a table in the far corner of the dining room that extended out into a solarium-type area. The cold outside that seeped through the windows and into the corner of the dining room made me unsure if I wanted to remove my coat, but I stayed in the corner anyway. When the couple entered, I first recognized Jake as he and his wife came into the dining room. Jake sat across from me at the table with his wife beside him, closest to the window. She kept her coat draped around her shoulders and I wondered if I should have chosen the warmth in the center of the dining room over the chill that was apparently paired with privacy. The waitress responsible for our table appeared very familiar with the couple and smiled as she filled my coffee cup and refilled their glasses of soda several times during the time we spent together. This location was a little more subdued than the previous day at Steak & Shake but still, I worried about the low level of privacy of the two locations and how that might negatively impact the interviews. My concerns were put to rest as Jake shared his stories without hesitation, with little to no apparent distraction by the din of the other diners.

Jake was a tall, slender man, with a smooth shine to his face that left him looking much younger than his 78 years of age. He had a gentle expression, bright blue eyes, and a big smile that made it him easy to talk to, like we already knew each other. At the time of the interview, he had been married to his wife for over 50 years and lived in a community in central Illinois that consisted of four houses and a grain elevator. While he was older than 65, the upper point of this study’s age parameter, Jake was burned at the age of 61 and he told me his burn event changed the course of his employment history. He said he retired the day he was burned.

Before his burn event, Jake not only farmed his land with corn and soybeans, he also had worked at the local grain elevator which was where the burn event took place. He told me the
story of how the gas line had been disturbed by a back hoe several days before the accident. He was turning on a gas line that fed the grain dryer when the gas line ruptured causing an explosion. That was in 1996 and I could see only small hints of scars and grafts in the exposed areas of his skin although he had sustained 65% TBSA of first, second, and mostly third degree burns.

“Yeah…and ah, it [gas line] went to the dryer and that valve was turned off. So I said they’re all on so I turned that valve on and as soon as I get it on, I could see something being pushed up like like dirt and dust out of the ground. Well I knew that wasn’t right so I started to turn it off and the next thing I knew I was on fire. There were vaporizers and a couple of pilot lights over about 25 or 30 feet away from me…that had just ignited…on fire. I ah dropped, and well I got out, ran out of the fire dropped and rolled…thank goodness…like my mom taught me to.”

He laughingly boasted about the cultured skin that covered his forehead and showed me the almost full-thickness donor site just above his ankle where the tissue had been harvested. I told him he was the only burn survivor I had met who had the pleasure of growing his own skin and that I was duly impressed. He smiled and then laughed some more.

Jake had been involved with the burn support effort that was provided by some of the survivors who had been treated at MMC. Prior to the Health Information Portability and Accountability Act (HIPAA) restrictions that limited movement within the hospital by non-employees or volunteers in an effort to protect patient confidentiality, a group of retired and disabled burn survivors had volunteered to visit burn patients on the unit to encourage them and answer questions for the patients and/or their visitors. He smiled often throughout the interview, even when speaking about how the cold and heat had become restrictive, making it difficult to
engage in outdoor activities like he used to. Jake didn’t share his post-burn history of cancer during the interview but his wife told me about the two episodes he’d experienced with one tumor found wrapped around his bowel and the other in his prostate gland. In spite of the physical limitations brought about by his burn injuries and illnesses, he described his health and quality of life as very good, but qualified his answer with “for what I’ve been through.” He spoke proudly about how he had discovered ways to enjoy his favorite outdoor activities such as University of Illinois games by accessing the “disabled” seating that was in the shade and driving a covered, air conditioned tractor for his son who farmed the family’s land.

I interviewed Jake as his wife sat next to him at the table. Jake told me that he and his wife had participated in this type of interview before and shared the story about their meeting with the author of a book in which their wedding story had been featured. Jake provided an amazing amount of detail about his burn event as well as his journey toward recovery including an emergency trip back to the burn unit after a serious infection had set into the wounds on his back. He provided great detail as to the treatments used to eradicate the pseudomonas and staph infections that included the painful application of an acidic preparation that was administered through moist towels laid directly on the wounds and followed by warm tub baths.

Jake’s wife was much more soft-spoken than her husband and reflected on her perspective of Jake’s burns and the recovery experiences, informing me of some of the negative details about his health that Jake had left out. It was after our interviews that Jake mentioned another burn survivor who might consider participating in this research and offered to contact Trooper to see if he would meet with me. Following the two interviews, Jake and his wife invited me to join them for pizza however I declined and headed home, thanking them both and then leaving them behind in the dining room to enjoy their lunch. As I drove the three hours
home, I wondered if I should have stayed to eat lunch with the couple, but then remembered that I had more participants to interview in just a day and a half and I was unsure if staying would compromise my position as a researcher.

The next five interviews were conducted in the conference room adjacent to the burn unit at MMC. This location was chosen by the survivors as being most convenient for them. The room was relatively private and warm, only interrupted by a random nurse or aide wandered in to retrieve lunch from the refrigerator or get a cup of coffee, or the sound of an occasional announcement from the hospital intercom paging a physician.

Steve

Steve was my third participant interviewee. He and his wife arrived for the interview promptly at 9:00 A.M Sunday morning. At first I didn’t recognize Steve as I met him at the door of the conference room. He appeared awkward as he came into the conference room and chose a chair directly across from my audio recorders that were already set up on the long white table that ran the length of the small conference room. His wife sat beside him and busied herself by reading the Sunday paper as I interviewed my participant.

Steve’s interview was much more difficult than those with Beth and Jake. His answers to my questions reflected minimal affect and consisted of brief, often incomplete sentences that required a good deal of probing. Steve was 37 years of age at the time of the interview and had the most recent burn event, occurring just over one year before we spoke. He was muscular with dark brown hair, and was married with two children still living in the home. He often shyly looked over at his wife, asking her for clarification or to confirm his recollections. Steve was burned over 40% TBSA of his upper body when the gas from the tractor he was working on
sprayed onto his shirt and was then ignited by the spark from the motor when he tried to start the tractor.

“It happened June 4th, 2011 (turns to wife for confirmation). Yeah, 2011…I was working out on the tractor Saturday afternoon, trying to bale hay…it wouldn’t run so I towed it in out of the field and went in for lunch then come back out to work on it…got…gas sprayed out of it and I caught on fire by the spark of turning the motor…shirt caught fire, half, well the right side and the front…half front well the right side and the front…half front all sleeves and then the back….I mean I stopped dropped and rolled but it didn’t get it out, I had to rip the shirt off”

At the time we spoke, Steve and his family lived in a small rural town near Clinton with a only few neighbors. The houses on their road were widely spaced by acres of farm land.

Steve proudly told me that he had gone back to work after most of his wounds had healed and that, thankfully, his boss had had him move to a less physically demanding job that actually turned out to be a promotion. His new job was Maintenance Supervisor at the plant in Bloomington and he also continued with his “part-time” farming. He smiled sheepishly as he repeated his words “yeah, part time farming” when I summarized the information from our interview together. I could only imagine farming was more of a hobby than an occupation. He described his quality of life and health as good and that it was basically unchanged since sustaining his burn injuries. Interestingly, Steve had an idea of what was involved with burn treatments and recovery as his father had also been burned at the age of 36 when Steve was still living at home with his parents. While he was in the hospital, he spent a lot of time worrying about family finances and if his young son might also be destined to experience a burn injury when he was 36, just like his father and him.
Following my interview with Steve, I interviewed his wife who had volunteered as a “significant other.” While Steve had provided limited detail and affect describing his burn event and journey toward recovery without probing, his wife provided an unbelievable amount of affect and detail. She sobbed openly as she reflected on the family’s experiences both during Steve’s burn event and after like she had never been offered the opportunity before. She provided important details about their family’s involvement in Steve’s burn injuries that her husband had not shared that included scenes such as their eleven year-old son who had been sitting atop of the tractor helping to put out the fire and running for the hose Steve used to soak his wounds while he waited for the ambulance, and then finding his mother’s shoes so she could ride with her husband to the hospital. I asked her repeatedly if she wanted to stop the recorders however she refused and continued on, wiping away her tears with the tissues I had brought in from the burn unit. It was during the interview with Steve’s wife that I saw his tender side as he spoke softly to her, encouraging her, sometimes appearing surprised by her emotional pain. He watched her closely with gentle eyes and touched her hand as she cried. It had only been a year since Steve’s burns and the emotional wounds associated with the burn event were still tender for both of them. I suspected that it may have been the first time Steve had heard his wife’s version of his story. Following the interviews, I thanked both Steve and his wife and asked if they were ok. They assured me they were “safe” and said goodbye. Steve walked close to his wife’s side as they exited the door and proceeded down the long hallway toward the elevator.

Matt

Matt and his wife arrived shortly after Steve and his wife left the conference room and the couple sat across the table from me for the interviews like they had been there a thousand times before. I sat across the table from Matt and interviewed my participant first and then his
wife who had volunteered as a “significant other.” During his interview, Matt looked over at the coffee pot on the other side of the room and asked if I was going to offer him any. I felt embarrassed by my apparent failure as a host because I hadn’t thought to offer anyone coffee, particularly since it wasn’t mine. I got up and quickly filled two Styrofoam cups from the pot and handed the dark, steaming cups to my guests. Matt spoke in a clear and concise voice and I could imagine him as a man in charge of his life. He provided in-depth facts and details about his burn event and journey toward recovery with minimal emotion except when his voice cracked as repeatedly told me that he hadn’t done anything wrong that day he was burned on the electrical sub-station. He said he hadn’t known what had happened to cause his injuries until a co-worker told him about the sub-station being energized. His emotional side began to reveal itself more fully when I interviewed his wife as his “significant other.”

Matt was 64 years old at the time of the interview and married with three children that were grown and out on their own. He lived with his wife in a small rural community with a population of 800, just south of Springfield. He was of average height, slender, and fit. He carried himself in confident manner, and never revealing the family nickname [a shortened version of his last name] that his wife used when referring to him. He had no burns scars that were visible, but must have been hidden by his long-sleeved flannel shirt and trousers. Matt was burned over 33% TBSA of his body by an electrical arc that caught him in 1999 while working as an apprentice for an electric company.

“…I was taken off the job site and ah, er…when we got there in the morning, and brought [it] back back on while I was away, they had ah…hooked up the portable sub to a live line….and I was unaware of that and I went back to put some bolts back on that portable sub-station…there’s a lot of bracing that goes on when we transport it down the
road so we don’t break insulator stacks….and we had taken all of that and I told a guy that I was with…we were going to do another job inside the sub-station that was existing. And I told him I was going to put the bolts back on the portable so I didn’t lose them…I had them in my jacket pocket and I went to put them back and uh, I didn’t know that it was energized, because physically the look of the sub-station did not change. All of the switches were open…I could see that because the blades were in the vertical position not a closed position which is horizontal. That jaw end was energized at 35,500 volts. And I (long pause) sat up on a piece of angle iron so I could reach up and put a bolt in and I got shocked. I don’t think I ever touched it ah but I got real close, I got close enough that it arced.”

Matt was very clear about his memories regarding his burn event, indicating that a co-worker had told him later, “I saw you on the deck and you weren’t moving, and you were smoldering.”

Matt had been remodeling the family’s home at the time of his burn event and while he was recovering on the burn unit at MMC, he worried about his wife and kids who were left in their dismantled home without him. After being discharged from the hospital, Matt wasn’t allowed to go home because the house was filled with construction dust and debris. So Matt and his sister, who was a nurse and wanted to help care for him after his release from the hospital, moved into Matt’s sister-in-law’s house until his house was put back together by community members. It was fifteen months before Matt was healed enough to return to work but was extremely proud that he had retired from his job with that same company in August of 2012. He described his quality of life as improved since his burn injuries because it had made him “a more grateful person.” Matt’s wife was very supportive of her husband throughout both his interview
and hers, smiling proudly as he spoke and reaching over and touching his arm on multiple occasions.

As his “significant other,” Matt’s wife answered questions about her husband’s burn-related experiences and also about their grown son who had been in the MMC burn unit when he was a toddler. She broke down several times and cried softly while she was being interviewed, particularly when she spoke about his burn event, hospitalization, and her fears for his health during those difficult times within his recovery and the fifteen months he worked to restore his strength and regain his independence.

Matt’s wife told me about the emotional side of her husband’s recovery as well as the affective impact it had on their family. It was during his wife’s interview that Matt’s eyes welled with tears several times as she spoke of how his burn event and journey toward recovery had changed the lives of everyone in their family during his hospitalization and the long months of convalescence; but I suspected it changed their family in general. She spoke about their teen-age son who had been burned as a toddler wanted to drive alone to the hospital to see his dad rather than ride with his mom and sister. She said he must have needed time alone and she had been worried about him too. She dabbed her eyes with tissues as she reflected on when she first heard about her husband’s burn event, the calls to her children and pastor, the drive to the hospital in Springfield, and the difficult months that followed as Matt struggled to regain his strength, whether it was preparing a salad for dinner or completing all of the exercises at physical therapy.

Matt’s wife spoke of when she first saw him in the hospital and he was aware enough to be concerned that his eldest daughter wasn’t present until she assured him his daughter had been notified about his injuries. Throughout both interviews, the two looked over to each other in a way that only two people who had shared a lifetime together could, sharing a gentle touch or
soft, comforting words whispered between them during periods when the subject matter became more emotional. At the close of the interviews, Matt helped his wife with her coat and after I thanked them both, they walked out of the conference room and down the long hall to the elevators, side by side and holding hands. My interviews were done for the day so I returned to my hotel room where I could give thought to what had been said, make entries in my field log and reflexive journal, and sleep before the three appointments that were scheduled for the next day.

Dan

The following morning was Monday and I knew it was going to be a busy day with four interviews scheduled. At 9:00 A.M. I greeted Dan at the conference room door. He had come alone to the interview and was quick to tell me this wasn’t the first time he had been interviewed about his burn injuries. Dan brought out a large manila envelope and dumped an array of photographs onto the table. There were several photographs of him sky diving and several more of him crossing a marathon finish line with his arms held in the air in triumph. He also shared a printed copy of his “story” that had been published in a Classic Corvette magazine several years after his burn event. Dan had been a speaker at a past burn survivors’ recognition dinner and was accustomed to talking about his burns and his journey toward recovery, and telling his “story” to people he met in his personal and professional life when he felt it was necessary or appropriate. He answered my interview questions with great depth in a very “matter of fact” way, telling me that he had told his story so many times that it didn’t bother him to talk about any of it anymore. As I asked my interview questions, I could tell when I touched on new material that might not have been part of his story because he would pause before providing an answer, asking me for clarification on several questions within the interview.
Dan was 44 years old when we spoke, average in height, with an athletic build. He was the survivor who had the most apparent grafts and scars, with burns on his arms and hands. He was missing several fingers on his left hand, and tight, thick grafts and scars creeping up his neck and onto his face, restricting movement of his head. Dan had a confident way about him, with a quick smile and a dry wit. He told me he had married his longtime girlfriend a little over a year ago and lived in a suburb of Springfield with his wife and her two children. He was 21 when he was burned, younger than any of the other participants at the time of their burns. He had sustained 36% TBSA burns, with first, second, and third degree burns that covered the upper half of his body. Dan was burned in 1990 when working on his father’s classic Corvette during his winter break from college.

“…it was a January day so it was cold and dreary out but no snow. Ah….but I was changing the fuel pump and it was leaking and the gas fumes hit…flashed…hit a kerosene heater…drifted over…the fumes drifted over and hit a kerosene heater and it flashed back and it caught me under the car…I heard the ‘poof’ and knew immediately what what had happened…or that I was on fire. So I rolled out from underneath the car…and as soon as I rolled out from underneath the car, I started to run out of the garage and I saw a blanket. I picked it up and I wrapped it around myself and rolled against the wall of the garage…that didn’t seem to do anything”

Dan described his primary concern while recovering on the burn unit was first his hair which burned and was subsequently shaved away by the nursing staff on the burn unit. After that, he worried about father’s two classic cars that burned with the garage. He worried that his hair might not grow back and that his father would be angry with him about the cars. Compounding the burn experience, Dan’s father never forgave himself for opting to go the auto parts store to
buy a fuel rather than send his son. Dan said he hadn’t been able to help his dad release his feelings of guilt.

Dan parents were divorced so he convalesced at his mother’s home after being discharged from MMC’s burn unit. He had recovered enough by the following summer to return to his studies at SIUC where he graduated with a degree in business management. He said he was challenged by the heat of southern Illinois while wearing his Jobst pressure garments [heavy, elasticized garments used to decrease scarring and redness in the burned areas], especially the full hood that covered most of his head and face.

Dan told me that his burns have influenced all aspects of his life but that he had accepted the changes they brought about and described his quality of life as “not bad.” In spite of his physical limitations, Dan’s burns had not restricted his personal ambition and drive. He said he worked full time at the area power plant, had a 5th degree black belt and teaches Kimbo Karate, had parachuted out of an airplane, and run in and finished more than eight full and half marathons. When asked about relationships, Dan told me that his burns had actually made him stronger because he had to overcome the visible aspect of the scars and work on his people skills, but the experience and the scars hadn’t changed him on the inside.

When all of my interview questions had been answered, I helped Dan collect the photographs of him that he’d laid on the table so that he could take them with him however he insisted that I keep the pictures to include in my dissertation. I wasn’t sure how I would include them but decided not to risk offending him by rejecting his offer so I tucked the envelope into my bag for safe keeping. I felt sheepish as I mentally considered how much time would be adequate before I could safely return the photos to him in the mail. As Dan put on his coat I thanked him for making the trip down to the hospital on his day off, we said our goodbyes, and
as Dan headed down the hallway toward the elevators, I closed the heavy wooden door to the conference room to prepare for the next interview.

Sanders

At 1:00 PM, I met with Sanders who also came alone, explaining that his wife who had originally planned to participate as a “significant other” was unable to attend. He appeared shy and awkward as he asked me where to sit. He sat in the chair I motioned to, leaned toward the audio-recorders, and answered all of my interview questions in record time. Unlike my previous participant interviews, Sanders described his burn event and journey toward recovery as not creating any significant life disturbance at all.

Sanders was 58 years old, married, and lived with his wife and dog in a rural community in central Illinois at the time of the interview. He was a stout man with a barrel chest and an apparent quiet nature. Sanders sustained a 40% TBSA burn that occurred when he was scalded with boiling water while blanching vegetables.

“Ah, I was processing some sweet corn in order to freeze it because we had an abundance of it. Ah that process involves blanching…where you put the sweet corn in hot water for a period of time to kill the bacteria and that sort of thing and then take it out and cut it off and put it in whatever container and freeze it. Ah…I tripped over a propane line and pulled the pot and the burner down on top of me as I fell. So that’s how I got the burns.” Sanders minimized his burn injuries, and stressed that the scars and grafts were hidden under his clothes and had not restricted him from most activities. He reported he had a relatively “easy time of it” and that he recovered quickly compared to others he had seen on the burn unit and at the survivors’ dinner. He attributed his sense of calm during the burn event and his inpatient treatment on the MMC burn unit to the time he had worked as an EMT in the small community
where he lived. He said he never had any thoughts “of impending doom” following his burn injuries and that, outside of the fragility of the areas that were grafted that tore open at times, he had no real physical limitations. Sanders said his quality of life was “essentially the same as it was before the accident” however never mentioned whether his quality of life was good or bad. As I asked him the interview questions, he provided limited detail and even less affective response. I began to wonder why Sanders had offered to participate in the research at all since his burn injuries hadn’t made much difference in his life. He had told me he enjoyed attending the annual burn survivor’s dinner but that made no sense to me either if he didn’t seem to identify as a “burn survivor.”

When we were through with the interview and I had turned off the recorders, Sanders looked at me with a very serious expression, leaned toward me and said that he felt it was important for him to participate in this research to help future burn patients, even though he felt his burn experience was minimal. I wondered to myself that if his wife had attended, I might have been given a very different perspective on his burn-related experiences. Sanders left the conference room while putting his coat on as I thanked him for his participation.

**Trooper**

The last interview of the day was with Trooper. Trooper had not volunteered at the burn survivors’ dinner however I remembered meeting him there as soon as I saw him. He had been recruited by Jake whom he met during his hospitalization on the burn unit. Trooper was a serious man who spoke slowly as he gathered his thoughts, providing detailed responses to my interview questions. Trooper had sustained the largest percentage of burn injuries of the survivors I had interviewed for this research. He was also the only survivor who didn’t have anyone to help him following his discharge from the burn unit, a situation I hadn’t even
considered prior to meeting him. However, Trooper wanted no sympathy and said he had lots of friends now and that his lack of social support was short lived. When he was physically able, he struck out to meet other burn survivors in the region, eventually volunteering to talk with patients and their families on the unit. This opportunity, Trooper told me, allowed him to do something he had always wanted to do with his life. He wanted to help people. All I could think as I listened to him talk was that he was amazing and could have been a “poster child” for resilience.

Trooper was a tall, very slender man who came into the room with arms and legs that appeared stiff, making him look brittle. He had a raspy voice that is indicative of smoke inhalation and/or being intubated for an extended period of time. He was 64 years old, single and lived alone when we met. He wore a light jacket despite the cold winter wind of central Illinois, and a drab green baseball-type cap that displayed an army insignia. Trooper appeared uneasy when he sat down for the interview and said it had been a long time since he had been on the fifth floor and he felt a little anxious. He carefully removed his cap and gently laid it next to him, and began to talk. He had come to the interview to tell me his story in the way he told it to everyone. I almost didn’t have the heart to interrupt him with my interview questions, but I remembered my role as a researcher, and I did. Trooper was burned over 94% TBSA of his body in 1991. He said he was just going about his morning routine with plans to go fishing that afternoon.

“I was in a house explosion. I got up one morning to fix breakfast and the first thing I done when I got out of bed was always put the coffee on…so I got up and lit the stove and it took two walls [of the house] and I don’t know what all…I don’t remember what all it did do but that’s how it happened. See, ah, this is a problem because all I remember is walking out and some neighbors come over and apparently I had a power line that went...
to the house and it come down…and I walked all across all that…and ah, they set me
down on the ground and I passed out….I didn’t know anything for two months.”

Trooper only had a sister who lived out of state and an elderly aunt to provide him any support. He told me that once his sister realized he was going to live, she bought him a mobile home in the small rural community in central Illinois where he’d lived ever since. He said he wasn’t able to return to work after his burn injuries due to his physical limitations, and I didn’t press him for what his job had been.

When Trooper was discharged from the burn unit, he was transferred to a nursing home because he didn’t have anyone to help with bandage changes and wound care. The burn unit nurses had purchased a pair of shorts and a t-shirt for him to wear out of the hospital because all of his possessions had burned with his home. He spoke sadly about the month he had spent at the nursing home and that once the clothes presented to him by the burn unit nurses went to the laundry, he never saw them again. Because he had nothing more to wear except a pair of shorts that were too small, the clothes that were actually returned to him from the laundry in place of his own, he chose to use blue Jobst pressure garments instead of “flesh tone” so the elderly women in the nursing home wouldn’t think he was naked. He said he had worked very hard to be released from the nursing home but before they would let him go, he had to prove to the staff that he was capable of preparing a meal. He leaned in toward me as he told me that he really didn’t do it alone; the nursing home staff helped him. Once home, he had to exercise his creativity in the absence of family support. He told me he had always been handy, and demonstrated how he had fastened his Jobst garments by hooking them on a nail in the wall.

When I asked Trooper about his social relationships, told me he hadn’t dated since he was burned, if that is what I was saying. He added that he didn’t think it was “fair” to them what
with his limited financial situation. His reasoning was that he didn’t have the financial resources of other men but I was unsure if that was the extent of it. Trooper was also involved in the group of men that visited burn patients on the unit at MMC. He took great pride in his ability to help people after his burn injury and credits his burns for providing an opportunity to be of service to others. When asked about his quality of life, Trooper described it as “a lot better than before” his burn injuries, “I don’t have so many things to concentrate on…I just concentrate on what I’m doing and enjoy life…the rest is of no importance.” He had survived “massive” burn injuries and was still focused on helping others as he answered my interview questions. At the close of the interview and after I had turned off the voice recorders, I took a long look at his cap with the Army insignia and asked if he had been in Viet Nam, to which he nodded. I added, “and all of this happened to you after you came home,” and he nodded again. Trooper slowly stood up from his chair and put on his jacket and cap. I thanked him, we said our goodbyes, and he walked slowly out the door like it might be the last time he would ever be back to the fifth floor.

Sid

Meeting with the eighth participant was more of a challenge than for previous participant interviews and after two failed attempts to meet, we finally met at a Denny’s restaurant in Evansville. I had no real choice of where to sit in the restaurant that was filled with the Saturday morning breakfast crowd and was seated in a booth just behind the juke box next to the door. When Sid entered the restaurant, he said he could tell it was me when he saw me and came over to sit down in the booth directly across from me. He asked me if I was going to eat and said he couldn’t because he didn’t have any money. I offered him breakfast and he ordered as I prepared the audio recorders for the interview. Sid munched on his bacon and eggs as he

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answered my research questions, providing in-depth details of his burn event and his journey toward recovery.

Sid, a 49 year old man, was in the process of a difficult divorce when we met, explaining that he had been in jail on a domestic battery charge the previous time we had scheduled an interview. He said his wife and kids were still living in the family home and he was living with friends. Sid had a soft smile and a gentle way about him as he sat at the restaurant table eating his breakfast while we talked and I found it hard to imagine him as a “batterer.” He was thin, almost frail, dressed in old clothes that were clean but heavily worn. I don’t know why I remember what he wore more than the other participants. It might have been because his clothes hung on him in a way that made seem weak and fragile. Sid had sustained 98% TBSA burns in 2008 and still had wounds that had not completely healed. He blamed his burn injuries for his current marital problems as his wife had been the person who was primarily responsible for his extensive wound care after being released from MMC and their relationship hadn’t been the same since. Sid had been an oil field worker like his father, living in a small rural community where almost everyone in town was either a farmer or serviced the oil wells that peppered the farmers’ fields of central Illinois. Farming and oil field work are occupations that often included the risk of burn injuries. Sid had not participated in any burn support networks however I believed his story was important to include in this study given the magnitude of his injuries and the impact his burns made in his life. Because burn injuries were common in his community, he had not felt alone or different because of his burn-related experiences. His whole body trembled as he told me the story of his burn event, but he wanted to continue to tell his story in spite of my offer to stop the recorder.
“I’d say I was fifteen feet away from the well. Well about ten minutes later it’s still blowing oil and it hadn’t …if anything it had increased in pressure not decreased…I distinctly remember Sam taking his glasses off and setting them on the bumper of the pulling unit which was right beside him and saying ‘shut the well down’…well after putting his glasses on the bumper, he hollered out ‘shut it down, shut it down’ meaning shut the water pump, shut the pump down. Glen took it upon himself, the water truck driver, to go over and switch the off switch on the pump…The pump kept running with the switch off, so then he took a screw driver or a wrench, I’m not sure, some kind of tool and he shorted between the spark plug and the frame and tried to short the pump to shut it off. When he did that, it was an old diesel engine and it backfired…and when it backfired, the entire area, say maybe fifty yards high exploded…because what nobody had realized it was not only just blowing oil, it was blowing gas and the whole area was gassed up.”

Sid was not the only one injured in the blast. He was one of the two men on site who survived the explosion and fire; the other two men standing closest to the oil well burned to death right there in the farmer’s field. Sid said that after tearing off his clothes and beating the blue-green flames out that burned on his skin with his hands, he just lay in the grass and waited for the helicopter to come and take him to the hospital in Springfield.

Sid told me that at first he was really angry about the explosion when he regained consciousness on the burn unit. He wasn’t mad at anyone in particular, like the owner of the well or his employer, but that the explosion had even happened at all. He struggled with nightmares and delusions while on the unit and at one point was put in restraints to protect his safety. He told me that he understood how someone in the hospital could jump out of a window
like some woman he had read about in the newspaper. He said he was certain at one point early in his hospitalization that if he could just climb through the window, he could see his kids who would be on the other side. As his recovery in the burn unit wore on, he felt he had “lost his desire” for life. It wasn’t until a family member reminded him of his wife’s four year old son and the importance of his relationship with the autistic boy that he decided he had a reason to live and began his work toward recovery. Sid did not to return to work and told me he was considered disabled and received Social Security Disability Insurance (SSDI) benefits.

Sid said he often thought about going out to a farmer’s field to stand near an oil well as a way to challenge his Post Traumatic Stress Disorder (PTSD), but at that point, he was happy the subtle smell of crude oil in the air around his home town in east-central Illinois didn’t stir his post traumatic symptoms anymore; or at least most of the time. Sid was very positive about his life in spite of the divorce proceedings and was happy that he had recovered enough strength to play a little ball with his brother and friends, but tired very quickly. He also told me he had to be very careful as his scars and grafted areas were extremely thin and fragile, and tore easily. Sid said both his grandfather and his father had sustained significant burn injuries that required hospitalization in the past. His father, who was also an oil worker, was burned on the job when Sid was just four years old. He said his father was one of his strongest supporters while he was hospitalized at MMC, and could be found on any given day sitting in the recliner in Sid’s hospital room watching one of the cable news stations. This interview lasted a little longer than previous participant or significant other interviews, as Sid shared his story and the effects the burns had on his family. At the close of the interview, I walked out into the parking lot with Sid, thanked him and said goodbye. I believe he left the strongest impression on me of all of the survivors, in that his burns were the worst and I couldn’t imagine how he could have survived.
Themes

After spending time with my participants and reviewing data which included participant interview transcripts, my reflexive journal and field notes, and the results of my pilot study, the themes that emerged through analysis were “How it Feels” to be a burn survivor, “…Somehow, I’m Still Me” after all I’ve been through, and “…And Yet, I’m Better” and found value within my burn-related experiences. Sub-themes within each of the themes emerged as being most prominent among transcripts and provided a clearer image of how these eight burn survivors experience major burn injuries and recovery. Within the theme “How it Feels,” sub-themes include pain and sensitivity to temperature, physical limitations, financial insecurity, body image, and social support. Within the theme “Somehow, I’m Still Me” are sub-themes of goal directedness and self-efficacy, humor, and insight that emerged during data analysis. Within the final theme identified of “This is How I’m Better,” emerged the sub-themes of spirituality, attributions for prayer, optimism, and gratitude.

“How it Feels”

Husserl (1936/1970) has been noted for criticizing the healthcare system for its dualistic view of the patient, maintaining a distinction between the mind and the body. Through a phenomenological paradigm, researchers have begun focus on the human experience by simultaneously recognizing the response of the mind and the body, with the body being the center of all experiences and essential for understanding of self, others, and the world (Moi, Vindenes & Gjengedal, 2008). Everyone has burned the tip of their finger on an iron or the stove, or gotten a “rug” burn on their knee. Usually the “victim” will favor that finger for a few days while the wound heals and the “heat” slowly leaves, or try not to bend that knee so the scab doesn’t crack.
When I was a facilitator for a burn support group and family members and/or friends of a patient would ask me what felt like to be burned, I would tell them that if they wanted to know what a burn felt like, they could take shattered glass and put it on the sticky side of thick packing tape and imagine what that would be like pressed against their skin. Then if they were really sure they wanted to know how it felt, they could put that tape down with the glass against their skin on whatever part of the body their loved one had burned. To imagine the burn after the skin’s surface is newly healed, remove the large pieces of glass from the tape, put it back on and wear it until you don’t notice it anymore.

Over the years that follow major burn injuries, the pain begins to subside as in a memory that will crop up at inopportune moments such as with a sudden movement to remind him/her that, although the wounds have healed, they are still there and need to be protected. The resilient burn survivor is able to set his/her bodily awareness of pain or discomfort aside as he/she stretched tight, tender skin and muscles and focused on what was positive and right in his/her abilities and environment. Participants in this study spoke of learning to compensate for lost or contracted fingers, stiff inflexible limbs, and fragile tender grafts and scars that felt foreign at first. Through the guidance of the nurses, doctors, and physical therapists, they worked tirelessly to regain strength, movement and flexibility. Participants knew the responsibility for moving toward recovery was on them as they set goals to regain autonomy and independence by retraining their bodies to reach their greatest potential. There were still activities that were more difficult for participants to engage in without a good deal of compensational creativity such as riding in a covered tractor or using “how to books,” and yet those successful resilient adaptations may be the first step toward recovery of both the body and the mind.
All seven of my male participants were able to incorporate the changes to their appearance and physical functioning without losing their important sense of self as they wove the burn experience into their life stories that were then shared with others. Even Beth had her burn story that she shared with me however her story became more of a justification for her feelings of disability than a challenge to get and be better.

Pain and Sensitivity to Temperature

The pain involved with major burn injury is almost unimaginably intense and can drive a person who loved life before burn injuries to feel like giving up, letting go, and fading away. Dan, Sid, and Trooper spoke of those times. As Sid lay in his hospital bed with massive burn injuries and the reality of his pain began to set in, he asked a doctor what could be done to let him die because he didn’t think he could go on. There was a time in the 1970’s, as treatment for major burn injuries became more successful, that medical ethics boards around the country would hear requests from family and patients that they be allowed to die if the doctors believed there was no chance for a descent life. There was a case heard by the New Jersey Supreme Court concerning Dax Cowert, a severely burned man for the times (36% TBSA) who fought for his right to choose death (Bogaert, Ogunbanjo, & Biko, 2010). I was lucky enough to meet Dax at a Phoenix Society dinner during one of their yearly conferences and in conversation he told me that despite the court’s affirmative decision for patients’ right to choose a good death as their course of treatment, he was glad to be alive.

Participants with greater than 30% TBSA burns spoke of a threshold when they realized that they chose life for whatever reasons they had to press on. Dan’s pain was so bad early in his hospitalization that he didn’t want to live anymore, “I just wanted to die because of the pain…” He acknowledged the “ups and downs” throughout his healing phase and how his sadness was
always diminished by the encouragement of his visitors. Sid’s the reason to live was an autistic child who needed him or the sense of responsibility and love Matt and Steve felt for their families. But not everyone considered death. Jake said he never gave death a thought and always knew he had reasons to live because his wife was waiting for him and there were grandchildren yet to be born that he wanted to meet. Pain was described by each of the participants as one of the main reasons they felt most comfortable in the company of other burn survivors who understood what they had been through. “People say ‘Oh, I know what you’re going through’ but they don’t….Because the pain of a burn is something that only people who have been burned know.” Matt described this sense of comfort being with other burn survivors as “an unbelievable kinship with these people…we can sit and talk about it,” like two old friends who were prisoners of war that could share in both the pain of survival and the successes of life as they learned to use their bodies all over again.

But the pain from the damage to the tissue does not end when the wounds have “healed” like a bone that eventually heals. One only has to imagine how burn injuries have unsettled nerve endings that result in chronic neurologic pain. Beth blamed her weight gain on the difficulty she experienced walking on the sensitive nerves in her feet that created an itching or a “pins and needles” sensation under her grafts and scar tissue. Pain also was also a consideration for the men who might have reached for something above their shoulders challenging contractures that restricted their arms from stretched, feeling like their skin would tear if they tried too hard or reached too high. When discussing their chronic pain, participants for both this primary study and my pilot study agreed that the pain was something that just needed to be moved to the background of their thoughts, and couldn’t be used as an excuse to not live life to the fullest.
The men within this study spoke of how their daily lives were affected by the weather. Jake, whose face was badly burned, said the heat made him avoid functions that would expose him to the elements for an extended period of time. Steve and Sanders said they kept their burns covered with long clothing, even in the summer to protect their sensitive scars from the sun. Survivors of major thermal burn injuries have a natural sensitivity to extremes in weather and temperature, whether it is hot or cold. Damage to the sweat glands occurs when sub-dermal tissue is burned, affecting the burn survivor’s ability to regulate heat. “I don’t ah stand the heat at all, I’ve lost…evidently ah my sweat glands were destroyed or something.” The inability to pass off heat through the sweat glands makes it difficult for participants to be outside in hot temperatures that may cause the body to overheat. Additional damage to available unburned areas of the body may become problematic after tissue is harvested for grafting, leaving behind additional damage to sweat glands and nerve endings.

Cold weather also causes difficulties for burn survivors in that the scar tissue becomes stiff and movement becomes difficult. This was a particular challenge for Steve and Jake who were farmers and required to be out in the elements in order to do their favorite type of work. “I’ve got this one spot right here (pointing to his chest) that might sweat if I really get hot. Other than that, I don’t sweat…ah so I I have a terrible time with the heat and cold wind really bothers me.” Resiliency theorists speak to the need for flexibility and adaptability in the face of crisis (Beneard, 2004). My participants shared a number of stories about how they were able to get back to many of the activities they used to enjoy like fishing after the sun goes down, riding on an enclosed, air conditioned tractor, or seeking out shaded “disabled” areas to recapture their ability to engage in important outdoor activities that were enjoyed prior to their burn injuries.
Burn scars around the joints, contractures in areas that used to be flexible before the burn injuries, and the loss of appendages due to deep tissue damage are not uncommon for survivors of major burn injuries. The skin might have been tight and inflexible restricting movement of that part of the body like Dan’s neck that prevented him from sleeping on his stomach or Steve’s shoulders that prevented him from reaching above his head. The scars and grafts may have been thin and fragile making the area vulnerable, tearing tissue like worn cotton fabric that finally gives way to an elbow or knee when there was a sudden move that required flexibility that just wasn’t there. Jake, Steve, and Dan, who had upper body burn injuries, spoke of restrictions in movement when reaching above their shoulders. Sid and Trooper, the two survivors with > 90% TBSA burns spoke of the need to relearn ways to do things as simple as feeding themselves or dressing. “I just figured out ways of doing things on my own. When you can’t do anything it’s a major problem.” Trooper summed up his adaptive abilities and successes saying, “It doesn’t make any difference if you are washing dishes or getting up to answer the phone, or getting up and getting a drink, you’ve accomplished a lot and you’ve got to keep it up.” Trooper had to work very hard to bend joints that were “locked up” in his leg and arm due to tissue damage and then lack of use over a long period of time. The fact that he could use all of his limbs to ambulate into the conference room was remarkable. Dan was missing several fingers on his left hand, just above the second knuckle. He said he was challenged by “tedious things” that required manual dexterity but that he just had to take a little more time with the tasks and was able to work around his physical limitations. “…and if I can’t do something with one hand I’ll use another hand to do it.”
Trooper found ways to accomplish any task he set his mind to by using “how to” books to direct him on how to do something, even if he had done it before. The adaptability, resourcefulness, and sense of mastery that was required by participants to find alternative ways to engage in any given task or activity that challenged their physical functioning were amazingly resilient and I felt honored that they felt comfortable enough with me to share such personal details of their struggles to regain independence and autonomy. But this very adaptability seemed to be the reason the participants made the decision to discontinue reconstruction of their burns. Steve said he didn’t want to start the healing process all over again without being certain the changes brought about by surgery would be worth the effort necessary to regain the movement he had at that point. “When we talked about going through therapy for another six months, I just…you know. I made it once, why would I reverse it?” As I talked with each of my male participants, I could sense they were more aligned with traditional male role expectations. They were men who worked with their hands and were the heads of their households. These were self-reliant men who were forced to be dependent on their wives and children and yet they credited the crisis that brought those changes that improved their relationships.

Financial Insecurity

Financial security is often challenged when someone experiences a major burn injury as it takes a very long time to heal enough to return to work, if the individual is capable of returning to work at all. Jake “retired” the day of his burn injuries and was involved in long legal battle with the gas company. He told me that the gas company had sent a technician out to test the gas line that had been damaged by a backhoe and certified all of the lines were safe for operation. Jake had worked a full-time job and farmed his entire adult life. He had a full career of taking care of his family and at the age of 61, all that changed and he could no longer provide for his
family. It’s believed that injury-related litigation is a factor in people not returning to work but yet, what about those who can’t?

Steve worried about his family’s finances while he was in the hospital in that his wife worked only part-time and he was the primary bread winner. “As far as finances and that…she works part-time but I’m the main one…that goes through your mind a lot.” Thankfully Steve had short-term disability insurance through his employer that helped with day to day expenses. Sid and Dan received cash support from friends and community members who were sensitive to their financial needs. Community members in Sid’s hometown held a fundraiser and then gave him a $15,000 donation when he was released from the hospital. Between farming accidents and injuries working on the local oil rigs, burn injuries were not uncommon in Sid’s hometown so the community members had experience with the consequential impact burns have on family finances.

Beth and Trooper were reliant on the generosity of their immediate families or government assistance for most kinds of tangible support. Trooper had nothing to start out with because everything he owned in the world was burned with his house. When he returned to the small town he’d grown up in he was able to re-establish himself within his community. Beth was receiving financial assistance from a community health program in Bloomington that provided both financial assistance for her necessary medications as well as general assistance for her here day-to-day expenses. She was required to work in the agency office one day per week doing paperwork in exchange for her general assistance. It’s important to note that Beth, Trooper, and Sid all lived either at or below the poverty line.

Sid had a long enough work history to receive federal dollars from Social Security Disability Insurance (SSDI). Although Sid talked about different types of jobs he thought he
could do, he said that with his financial responsibilities for five kids, it didn’t make sense to take a low paying job that he might be physically able to do and loose that support from SSDI. Going on disability was a difficult decision for Sid because his father went back to work out to the oil fields after he was burned and Sid struggled with what he should do about his employment situation and also what his dad thought he should do. “He wasn’t part of the Great Generation, but he’s the son of that Great Generation….And he grew up hard and when he got burned there was no worker’s compensation, no suing your employer…As soon as he got out he went back to work and he…he’s not a complainer and ah…he intimidates me.” Sid was conflicted by what he believed his father expected of him and what he expected from himself. I know that it meant a lot to Sid to know that whenever he woke up, his father was always in the recliner watching television in his hospital room. He didn’t want to disappoint him.

*Body Image*

Major burn injury is an assault to the body and leaves in its wake an altered physical form. The psychological stress involved with a threat of loss of self as a result of disfigurement is also dependent on social values and the person’s acceptance of their culture’s definition of beauty or what is considered valuable (Fine, 1991). Beth viewed her feet as the most appealing part of her body and was devastated by the scars. She made every effort in her power to cover them from everyone’s sight, even people she knew well. Dan, who was young and single at the time of his burn injury, felt that his burn injuries had impacted every aspect of his life including his self-image, but that he wasn’t bothered by negative reactions to his burns anymore.

I remember an important time within my journey toward recovery when, at the age of nine, my mother took me off to Chicago and bought an array of “Lydia O’Leary” make-up that was formulated specifically to cover large scars or deeply colored facial birthmarks. The process
required me to prepare my face with a special cream and then an application of a heavy base coat, then light and dark highlights, and finally the application of “drying” powder to set the make-up. I thought the make-up looked terrible, and made me look like the hookers I’d seen on television. I vividly remember a time after I had finished the time consuming task of applying the make-up to make myself look “better,” asking my sister if my scars looked so bad that it was necessary to spend an hour trying to cover them up. I stopped using the make-up after about a year and, at the age of ten, made the decision that it was important to embrace what I looked like with the scars. I didn’t wear make-up again until I was in my twenties, wanting to come to terms with my ever changing appearance as the scars matured and then were disrupted again by subsequent reconstructive surgeries.

The men were able to distance themselves from the social stigma that might have left them feeling marginalized by their appearance. By resisting the adoption of a negative self-image following their burn injuries, they learned to cope with the slow but steady changes to their appearance as they healed. “I look in the mirror every day and I see those scars and they’re a part of me…they ain’t going to change and they ain’t going to go away.” No matter how many years it’s been, the scars would always be there. What became important for the men was that they were able to incorporate their changed body image into positive self-esteem. They had survived and triumphed over their burns and they didn’t want to give up another thing because of them. On the other hand, Matt, Jake, Steve, and Sid had wives at home to help them adapt to their scars. “Ah you know she, she had to accept me with all those scars…you know…I had to do that too.”

In the beginning, it took a lot of effort to love myself when I looked different than everyone else that I met. It wasn’t until I went to the first burn survivor support group that I was
able to release a lot of the reservations I held for my appearance until I could sense whether it
would be accepted in a new place with new people. Matt and Jake spoke of grandchildren who
were initially frightened by their appearance when they first came home from the hospital. As a
child and young adult, my burn “story” became a defensive mechanism, telling my burn story to
dispel any tension at first meeting. Over time and with support from other burn survivors, I was
able to accept myself and my appearance with a sense of pride for my resilient capacities. The
seven male participants were able to incorporate the changes to their physical appearance
without losing their important sense of self as they wove the burn experience into the story about
their burns they shared with others. Resilience theorists believe that adaptive distancing and
resistance act as an internal protective mechanism guarding a person’s sense of self, supporting
positive transformative strengths (Benard, 2004). Beth was ashamed of her burns and I was left
wondering if the study results might have been different had there been more women in the
participant sample. But, I also wondered if it is cliché to think that only women are concerned
about their appearance or that women are judged more severely by the public.

Social Support

Jake, Matt, Steve, Sanders, and Trooper lived in smaller, more rural communities in
central Illinois and were each visibly moved during their interviews when they described the
outpouring of support from their friends and neighbors. When I asked Jake, who had always
been always been very strong and self-reliant, what it was like for him to have received
assistance from his friends and neighbors, he just sighed and with tears in his eyes, described it
as “humbling.” “Since this happened at harvest time, people came and harvested our crops (tears
welled up in his eyes)…and there was so many people I didn’t know how but the…the women
brought food and fed everybody you know…and the men had ah either brought wagons or combines. They harvested the corn and soy beans…it’s just overwhelming.”

Steve had a similar story in which his neighbors came and brought in his hay, mowed his lawn, and checked on his family while he was hospitalized on the burn unit. Matt, another proudly self-reliant man, was in the midst of remodeling his house when he was burned and wasn’t permitted to return home following his hospital discharge because of the construction dirt and debris that would put him at risk. Members of his community came out to his house with their ladders and tools and put his house back together under the watchful eyes of a contractor who lived in town, charging Matt only for the cost of materials that were required to complete the project. In addition to community support, members of Matt’s AA community were there to provide support. Matt concluded his story with, “That’s a rural community, you know?” It’s been found that social support is one of the most important predictor variables for positive health outcomes for individuals suffering “massive” burn injuries (Anzarut, Chen, Shankowsky, & Tredget, 2005). Social support may be provided in three discrete forms: instrumental (tangible), informational (information relative to the need) and emotional.

As I progressed with the interviews, it appeared to me that participants who were residents of small, rural communities enjoyed a greater level of acceptance than those who lived in the larger cities within the region. Jake, Steve, Matt, Sanders, Trooper, and Sid had grown up in or near their small towns and each of the six participants stressed that there were no questions asked about how the accident happened because everyone already knew. There were no curious stares when they were out and about in their communities because everyone had known them for a lifetime and saw them only as the person they had always known. Jake said, “I don’t know if they notice anymore. It’s been so long now (laughing), it don’t make no difference to them.”
They were accepted, and with that social acceptance came an element of self-acceptance by the survivors themselves.

Jake, Steve, Dan, Matt, Sanders, and Sid enjoyed an outpouring of support from friends, family, and community members who provided instrumental and emotional support following their burn injuries. When I first started the data analysis for this project I wasn’t sure if the outpouring of support was because of the men’s personal characteristics that endeared them to community members or the loving natures of the people living in participants’ communities. Regardless of the reason, friends and neighbors came forward to assist with tasks, including harvesting fields and rebuilding a dismantled home, that may have gone undone. “Ah, I live in a small town and of course everybody knows everybody…The small towns, everybody likes to help everybody…pitch in…and so that’s why I fit in so good.” Beth, who did not receive the same level of social support from the residents of her home community, was limited to the support of immediate family members and local social services. I was challenged by my experience as a therapist not to ask about her absence of social support. I had to be satisfied with the words offered by participants and not delve into areas that were not pertinent to the research questions.

When beginning this study, I had a sense that community size and connectedness would be important to participants’ long-term health outcomes however I wasn’t sure why. What I discovered, as the categories emerged through data analysis, was participants’ sense of community went far beyond social acceptance of their appearance like some kind of a gift. There was reciprocity within relationships that were shared between seven study participants and the other residents in the small, rural communities in which they lived. Jake told me, “They you know…We had a fellow that died after I got burned, I wasn’t able to do much as far as being
around the dirt at that time. I got my pick-up truck and hauled wagons into the elevator…it you know…turn- about is fair play… He was one of them that helped.” Resiliency theorists believe that resilience is an innate developmental capacity shared by all humans and that communities provide a kind of nurturing environment necessary for positive developmental outcomes (Benard, 2004). The social support fosters a sense of belonging and social affiliation that supports feelings of competence, autonomy, and safety within the individual (Benard, 2004). They knew they were not alone.

“Somehow, I’m still me”

It’s hard to imagine that after experiencing something as devastating as burn injuries one could possibly be the same. Between the nightmares, anxiety symptoms, the “highs and lows,” and the time spent away from one’s family and regular routine, it is hard to imagine that participants could even resemble the person they had been before their burn events. It is true that burn injuries cause irreparable damage to the body and leave the person altered, but those changes I was told, are primarily on the outside. When participants first became aware of their injuries, they described feeling raw and vulnerable when in the hospital trying to make sense of what happened to them, and then challenged at home as they tried to return to the lives they had known before their burn injuries.

Mirrors are rarely accessible on a burn unit for obvious reasons. “…and early on too, all I wanted to see was a mirror and they would they would never give me a mirror. All I wanted was to see what I was going to look like.” Participants spoke of when they first looked in the mirror after they returned home from the hospital and did not recognize themselves at first glance. But as their strength returned through hard work, they were eventually able to recognize themselves and their independence again. Eventually, the initial shock at their reflection faded
and the scars blended into their adjusted self-image. Participants told me that their outsides were burned but inside, they were still the same.

I remember being released from the hospital on my seventh birthday in November and returning to school after the Christmas holidays. I entered Mrs. Bigalow’s first grade classroom and sat at a back table with my best friend whom I hadn’t seen since the end of Kindergarten. I was worried about what I looked like because I still had bright red new skin and scar tissue and dark brown scabs on my face, but I received a warm welcome from my teacher and classmates who didn’t seem to notice. Thankfully, I was expected to resume my place as a student in class by paying attention during our lessons like all of the other kids, requiring me to pick up my previous role and move forward. Recently I asked a friend who was in that class with me if he remembers what I looked like when I came back to school and he said all he remembered was that it was me. Living in that small town allowed me to still be me, even though my face and limbs were changed. Over the years I’ve learned to think of the body as a container that provides us with a package to present to the world and to carry our inner selves. Much like the can that is dented in the grocery store, some people will avoid it and others will recognize that the contents are the same despite the damaged exterior, and will choose to take it home.

This resilience was evident within my participants, including Beth who knew that she wanted to be with her family. She displayed insight but her goal directedness and self-efficacy were limited to her immediate surroundings. I believe Beth might have taken a different recovery path had she been encouraged to be less dependent on her parents. She volunteered to participate in this study and that took courage and insight to answer my questions. Resilience theorists believe that adaptive distancing and resistance of negative self-image act is an internal
protective mechanism that guards a person’s sense of self, but also requires the complementary development of critical consciousness of one’s self and the environment (Benard, 2004).

Goal directedness and self-efficacy

I know that all eight participants were internally motivated based by the fact that they had the strength to get up out of their hospital beds and were able to leave the hospital and return home. Each of the participants said they came to an early realization that it would be their responsibility to work toward reclaiming their lives. Matt told me about the deal he made with God early in his hospitalization at MMC. His part of the deal was that if he did the work that was required to recover from his burn injuries, God would see to it that he could return to work and ride his motorcycle again. They set achievable goals within their healing and the journey toward recovery. The goals might have been to complete the exercises at physical therapy on a given day or to make the salad for their family’s dinner. They were aware that it would take all of the strength they could muster to follow their doctors’ recommendations and to do what the nurses and physical therapists told them to do. They wore uncomfortable Jobst garments because they knew that their scars would look better if they did. “Because it’s one of those things that until you’ve successfully…made it in your mind that you are going to get better, that is when you will get better.”

The goal directedness and self-efficacy of participants was also apparent within post-recovery activities such as Dan training for his eight marathons or a higher karate level, “I figured after after being burned, I could do anything, that’s why I did the marathon.” He knew within himself that he was strong and capable of almost anything he decided to approach. Participant goal directedness was evident when Jake and Trooper worked to rebuild their upper-body muscles by casting fishing weights with rod-and-reels in their yards. Steve made the
decision that he was going back to work but felt fortunate that he was given a change in assignment because he wasn’t sure how he was going to do his job which was very physical. With the exception of Beth, who continued to be very dependent on her mother’s support and direction, the men within my participant group all spoke of the goals they set both in the hospital and after returning home to regain their autonomy and as much of their lives as they could, a little bit at a time.

During the interview, Beth reflected back to the day before she was released from the hospital. She was afraid that if she asked for pain medication they wouldn’t let her go home. She said all the nurses wanted her to do was to walk to the nurses’ station and pick up the medication on her own. So she walked out of her room and to the nurses’ station to collect her medication. When I asked her about her goals and how they might have changed since her burn injury, she responded, “Yeah, I think I gave up on everything…uh (pause) my only goal was to be with my family.” All of my participants had a story about how the nurses provided them with challenges such as sitting up in bed, moving to sit in a chair, walking down the hall on wobbly legs with an IV in tow, and all they had to do was to meet the goals head on, “put one foot in front of the other,” and take it “one day at a time” as they continued their journey forward toward recovery.

_Insight_

Most of my participants exhibited great insight as I asked them pointed questions about their six dimensions of health. Sanders may have been the acceptation based on the limited depth in his answers to interview questions. For the other participants, there were questions that weren’t expected as they each paused to collect their thoughts before answering, providing sometimes long and detailed examples of whatever point they were trying to make. They were
capable of deep self-reflection as they talked about their hospital experiences and their emotionality when they finally realized the reality of their situations. Sanders said he never felt any sense of urgency or fear after the water and burner fell on him which he attributed to his working knowledge of burns from his time as an EMT. He told me he had an idea of what could be expected as soon as he realized he was burned and said he remembered the moment he was going into shock shortly before the ambulance arrived. He also told me he wasn’t surprised by the course of his treatment on the burn unit or after discharge, only that it took longer to heal than he had expected. Resiliency theorists believe insight is the deepest form of problem solving and is similar to the concept of critical consciousness, and is a necessary tool used to separate between individual perception and reality (Benard, 2004).

In spite of the massive nature of Trooper and Sid’s burns, they said they knew intuitively that they had to be patient with their slow rate of healing and extended recovery path, understanding that it would take time for their bodies to heal from the massive injuries. Trooper said, “…it was just ah a long journey…ah even after I went home ah…and didn’t…you know I just took it one day at a time and put one foot in front of the other.” Participant insight was evident within all of the participant interviews, including Beth. Beth had come to hate all feet, not just her own. She laughed when she talked about her foot phobia, saying she wouldn’t go to the doctor for her feet because she didn’t want to be touched by someone who had touched someone else’s feet. She acknowledged her thoughts made little sense but had the insight to understand her phobia served a purpose for her to not do anything more in terms of treatment for or reconstruction of her scarred and grafted feet. I wondered if she had felt better about her feet or her feet were less painful to walk on, she might held herself to a higher standard of
productivity, and pursued her education or employment. That would certainly have changed the
dynamic between her mother and her.

**Humor**

Humor in the face of pain was a game changer for my participants as they said they were
able to overcome much of their emotional pain by laughing instead of expressions of despair. As
a therapist, I might have been concerned that they were laughing “inappropriately,” making a
clinical judgment that they were not coping with the deep, dark reality of their situation. But in
fact, that was exactly what they were doing. They were making a choice not to be consumed by
their pain and fear by laughing instead of crying. Resilience researchers write about the
important use of humor that can be used as a powerful coping mechanism during stressful times
and holds the potential to foster positive social connections between people by transforming
negative emotions felt in crisis to positive emotions expressed through laughter (Benard, 2004).
Beth, Jake, Matt, Dan, and Sid used humor throughout their interviews, often laughing at
themselves or situations that might have sounded too serious for a listener to laugh at had they
not known or understood the context for their laughter. Jake stopped in the middle of a
description of his dry, cracked donor site used to harvest the skin for the culture and with his foot
propped up on his chair and pant leg pulled up to his knee, asked me if it was ok for a little
humor. After I assured him that it was ok, he told his story about a conversation he had with his
nurse while on the burn unit. “…this graft that they took off my ankle (pointing at his exposed
ankle), I said I’m sure glad you didn’t take it off my butt or I’d have been a butthead.” When
Dan was first out of school and applying for employment, he interviewed for a firefighter
position in front of a panel of men. When one of the men in the panel asked him why he thought
he would be a good firefighter, Dan said he looked at each of the men, rolled his sleeve up and
exposed the scar tissue and grafting on his arm and said, “…I can fight fires without equipment, just think if I had equipment. They didn’t know what to think.”

Even though each interview was the only time I had really sat and talked with each of my participants, I felt comfortable to laugh when they laughed, and share in their humor as they coped with the traumatic nature of their burn injuries and recovery. I have to admit it made me wonder if my efforts to be entertaining within my social relationships might have come from this same coping style shared by my participants

“Yet, I’m Better”

Alan Bresslau, founder of the Phoenix Society for Burn Survivors and a burn survivor, told me he chose the name for his philanthropic organization after the mythological story of the bird who after crashing into the fire, rose from the ashes more beautiful that before. After being burned in a plane crash, he spent his second (post-burn) career and a good portion of his personal energies working toward making the world a better place for burn survivors by educating the public as to what it was like to be a burn survivor and that burn survivors were not alone. He may very well have been the one who coined the phrase “burn survivor.” He worked tirelessly to bring the scattering of burn survivors from around the world together so that survivors could provide peer support for one another. What is important to note within these findings is that not one of the participants within this study or my pilot study would have changed anything about the day their injuries or not to have been burned. Each participant knew within themselves that they were better people because of what they had experienced and wanted to share that knowledge with others through our interviews together.
Feeling Productive

It is important to note that all of my participants were involved in some kind of productive activity within their communities, whether it was “scraping,” volunteer work, church, or AA groups. Even though Jake and Matt were retired, they each continued to participate in church-related and community activities, traveled, and spent time with their friends and families. Matt continued to be very active in AA. Beth and Trooper who were disabled talked about their volunteer activities and Sid was “scraping” for supplemental income. Beth volunteered one day a week at the Township program that provided her medical and general assistance.

Jake and Trooper had been volunteers who visited burn patients and their families at the MMC burn unit and missed the interactions with other burn patients and survivors the activity had afforded them. Trooper and Sid first experienced their disability in their forties, a time within their development that Lifespan theorists believe most adults are becoming stable in their careers. Sid and Trooper talked about what they might have done for employment or what they still might “be.”

All of the participants expressed a need to be productive. Matt said he just wasn’t a man that could sit around and do nothing, so he busied himself doing household chores as he rebuilt his strength, but the goal was to return to work so that he could provide for his family. Jake was a farmer at heart and it was important to him to get back to work on his land. Being so close to an age when retirement was acceptable, he embraced his retirement status and helped his son with the farming by riding in the enclosed, air conditioned cab of his new tractor. Dan pushed himself beyond limits that might have stymied people who hadn’t been burned, like jumping out of an airplane or teaching Karate in addition to working full time. As I looked at Dan’s pictures
that lay on the table, I thought to myself that there was no way I could run a half marathon, even in my younger days. And yet, there were pictures of him crossing the finish line with his arms up.

Sid was challenged to accept his disability status because of his beliefs about a man’s role in the family. His dad went right back to work after his burns and, somewhere not so deep inside of him, he believed it was his responsibility to do the same because that was what family men did. So he “scapped” metal on the side while he tried to figure out what he could do to bring in extra money and feel productive. Beth had tried to go back to school for a short time to study the laws that pertained to renters’ rights because she held her landlord culpable for her injuries and she wanted to do something about the “slum lords” in her community.

Being limited from participation in the workforce appeared to have left a negative impact Beth’s and Sid’s self-esteem. Trooper, on the other hand, was thrilled that his burns provided the opportunity to help people in a way that he had always wanted to but didn’t know how. I suspected that his time in the army may have been a factor in his employment history but I didn’t ask him any questions about his service-related experiences or memories. It wasn’t pertinent to this study and I was also worried about being able to return the lid on that subject once opened. Sanders was evasive about his employment status during the interview, even when asked, but that his injuries had not restricted him from being able to do the things he wanted to get done.

Seven of my participants were men who were accustomed to working with their hands and taking care of themselves, and if they had them, their families. I found myself wanting to convince them that volunteerism is a valuable and worthy occupation in the face of disability, but left it with a few encouraging words for the help they unselfishly offered to others. “The description of resiliency begins with any point in time when a person has adapted to her/his
situation in life” (Richardson, 2002, p. 310). After a crisis, the actions one takes to regain important dimensions of life are reflected in his/her goals and behaviors. Resilience theorists believe motivation toward achievement motivation is a key factor in a person’s ability to bounce back after a crisis (Benard, 2004).

**Optimism**

Common sense might suggest that of all of the bad things that could happen to someone, one of the worst had happened to my participants, and yet they remained positive in spite of their burn-related experiences. They each had stories about times when they were sad or worried about what they were going to look like after the bandages came off. Sid and Dan spoke of wanting to die rather than live through the pain, but even those feelings were fleeting and they both returned to their “ups” in contrast to their “downs.” “And one thing you got to keep in mind is think positive…no matter what happens because there are so many ups and downs with burns…and that’s held true a lot of times.” Trooper was depressed while in the nursing home and didn’t want to go to visit his sister over the holidays. When telling the story, he made a quick transition and turned the story into another direction. His story shifted to the positive experience of his brother-in-law taking him to Bass Pro Shop while he was visiting in Missouri. Sid met a little boy who was maybe four or five who asked him why he was wearing the blue [Jobst] suit. Sid started to beam at this point and said that he credited the curiosity of that little boy for “setting” him “free” from his fears about his appearance. He said after that, he just didn’t care about that stuff anymore. He was alive and that was what was important.

Whenever I think about Matt and his wife, I can’t help but wonder what their relationship was like before Matt was burned because he said his relationships were better since his burns. The affectionate looks Matt and his wife shared when they spoke of the improvements in their
marriage since the burns were really heartwarming. I have seen how difficult burn injuries can be on a family and how many couples fall apart under the stress. But these two people must have proven to each other that they were there for the long haul. And as they sat across the table from me in the conference room, I felt like I was witnessing a very special moment for them.

But the most impressive optimistic point for me was when each of the participants told me that they wouldn’t have changed their burn experience. Matt felt that his relationship with his wife was better since he had been burned. “So I, I, I think that it’s really important that…to keep a positive state of mind.” When talking about making plans for the future, Jake suggested that he and his wife had a lot to do yet. Jake, Matt and Trooper believed they were more optimistic after their burn injuries, believing they were more appreciative for what they had today rather than what they might not have had yesterday. “Ah ah, I just enjoy life more…ah, you know you listen to the birds and you feel the wind. You don’t complain ‘cuz it’s raining…ah, you just live one day at a time.” Steve and his wife attributed much of their family’s effort to get to know more people in their church after his burn event. Even Beth was able to identify more optimism after her burn injuries, and attributed her improved relationship with her mom to her injuries. They believed that being burned had turned out to be a positive influence in their family members’ lives. “It goes a step beyond the self-awareness and mindfulness of recognizing one’s thoughts and their role in creating one’s reality to the act of choosing to see the glass as half-full instead of half-empty or to say ‘yes’ instead of ‘no’ (Benard, 2004, p. 31).

These lovely people who came out on a cold January day were positive in the face of some pretty major life difficulties. Their lives were challenged by unplanned circumstances but yet they held on to their relationships and made every effort to be positive as they moved
forward in their recovery. Beth said, “Out of all of the bad things that could happen, the best thing was I think I found myself a little bit more after the burns…I found me.” Optimism is an important feature within Resilience theory in that the strengths/assets provide resilient individuals the cognitive tools required to focus on what’s positive within one’s life rather than to hang on to what is negative.

Spiritual Growth

The challenges associated with major burn trauma can crumble families and yet three of the four couples who were married at the time of the burn injuries were still together; the exception was Sid. Jake, Steve, Matt, and their wives attributed each of their family’s stability, in part, to their spirituality and connectedness to a church family. All eight of my participants had at least an appreciation for God, if not an established relationship. Matt and Jake were active members of their churches prior to their burn injuries and felt their relationship with God was strengthened as a result of their injuries. They each talked about important relationships they had with other church members and how important those relationships were in their spiritual lives. Matt’s wife referred to him as the family’s “spiritual leader,” and Dan believed that God was responsible for him surviving his burn injuries. Steve’s wife told me that since his injuries, their family had made more of an effort to attend church services and included prayer in their daily routines. Beth, who looked to her church as a source of community, felt she was more of a believer after her burn injuries and she had made more of an effort to pray.

Those participants who had not had an active relationship with a church family experienced their own special kind of spiritual growth. Trooper, who said he had no concrete definition for God prior to his burns, believed there was “something out there” which he credited for his survival when the doctors didn’t think he would survive. He summed up his spiritual
beliefs as “There, there is something greater than we are.” Sid had always thought of himself as a spiritual person, yet believed his spirituality had grown in the four years since his burn injuries. Spirituality and church affiliations were important sources of comfort and support for Steve, Jake, Matt, and Beth, as well as their families as members of their congregations came forward and provided instrumental and emotional support.

All of my participants found emotional comfort in their spirituality and their participation within their church families. They felt honored to be alive and attributed their survival to the benevolence of God and that their path from there on out would reflect that same type of love and generosity. “Researchers have found that some resilient individuals draw strength from religion, other’s benefit from more general faith or spirituality, and other achieve a sense of stability or coherence by finding personal answers to questions about their sense of purpose and self-worth” (Benard, 2004, p. 32).

**Attributions for Faith and Prayer**

It has been said that for a non-believer, prayer is something that people can do when there is nothing else that can be done. But a believer has faith in the power of prayer and the faith that their higher power can be petitioned for assistance. Beth, Jake, and Matt were honored that their names being added to prayer chains and attributed their current level of recovery to prayers offered up by others. Matt’s wife said one of the first phone calls she made after she heard the news of her husband’s injuries was to their pastor to put Matt’s name on the church’s prayer chain and that their pastor was already at the hospital with Matt when she arrived.

Jake believed his survival was likely due to the number of people around the world who were praying for him, including two exchange students who had lived with their family; a “son” from Brazil and a “daughter” from Iceland. “I just know there were a lot of people praying for
me and I had no idea they were praying for me when I was in the burn unit...and ah...in fact, people were praying for me and I had no idea they were praying for me. I mean just, there weren’t many continents that weren’t covered, I’ll put it that way.” It’s important for me to note that at the end of each interview I asked each participant if there was anything they would tell a newly burned person. Each of the eight participants and the four significant others said they would tell them about the need for faith in God and prayer. These sentiments were consistent with the four participants within my pilot study.

Gratitude

Gratitude was a prevalent emotion for all eight participants and their significant others, as well as my pilot study participants. Each participant expressed gratitude throughout their burn stories. It might have been the buddies who picked Matt up three times a week and took him to physical therapy and then to lunch where they made him laugh at himself for looking like a “whipped pup.” Or Steve’s young son, who scrambled off the tractor and ran for the hose and helped his mother locate her things after she called for the ambulance. Or it might have been gratitude for Steve’s father who was also present and tried to calm Steve who was anxiously waiting on the grass. Participants’ gratitude might have been for the tangible support that was offered by friends and family as could be seen and felt when Beth looked over at her mom and expressed how her appreciation for her had grown since her burn injury. Gratitude for their wives and families was evident when Matt and Jake looked at their wives who stood by them at their worst and loved them even more. For Jake and Trooper, their gratitude was for being alive when their mortality had been in question. “Yeah, I think it’s made me a more grateful person...ah, you know I get up in the morning and I’m grateful for the things that I can do.”
What was most surprising to me was that it didn’t matter how much less or more severe each participant had been burned, they were each grateful for not being burned as badly as someone else they had met at one of the survivor recognition dinners or on the burn unit. “There were a whole lot of people who had a worse situation than I did.” The two participants with the largest TBSA burn injuries were grateful to be able to walk outside and feel the sun on their skin. Sid was grateful that his face wasn’t disfigured because he didn’t want his kids to be afraid of him and Matt was grateful that he was able to return to work. Dan was grateful that he was able to accomplish the many things he set his sights on like finishing college, the marathons, and his black belt in Karate. Sanders told me he was grateful that he was healthy at the time of his burn injury and had supportive friends who came forward to help him as he recovered. Trooper felt grateful that all of his limbs were intact and the joints finally worked. He was also grateful he had been given the opportunity to help people on the burn unit. He was especially grateful for the little boy he’d met at a Bass Pro Shop while visiting his sister who’d asked the question Trooper had dreaded most. But when it was all said and done, Trooper felt at ease, no longer concerned about how he would react to public scrutiny. “He gave me a sense of freedom…and ah, he let me get on with what I had to do.”

What was most impressive for me was the gratitude every participant had for the burn unit staff and their doctors. Each participant told their own story about something memorable from their hospitalization in which a nurse said or did something they felt was inordinately compassionate or sensitive. It might have been when a nurse jokingly told Jake he needed a bath and rolled him into a hydrotherapy tub that was a soothing break from the pain. Or the times Jake’s wife called the nurses at one or two o’clock in the morning to talk because she was alone in her little hotel room and was worried. Sid spoke of the comforting words given by the
psychologist who normalized his panic when he saw the wildfires on the television as his father watched the news. Trooper was grateful for the physical therapist who finally helped him bend those locked-up joints in his elbow and his leg. Matt was grateful to his doctor who was honest with him and pushed him to be aggressive with his treatment. He was also grateful and appreciative of his doctor’s dry sense of humor that made him feel more at ease. Beth was appreciative that the nurses were so nice to her and Dan appreciated that the nurses were honest and told him when something was going to hurt, giving him the freedom to express his pain. Matt and Steve’s wives were grateful that they could return to work and their children knowing their husbands were safe in the care of MMC.

Each survivor and their significant other spoke of how wonderfully they were treated despite the difficult and painful nature of treatments that were involved. It was a simple as a kind word at the right time, and providing support for a loved one on the phone after visiting hours. “It makes a difference when you’re talking to someone who cares.” These findings are consistent with my pilot study with participants who were hospitalized in another hospital, in another city. They were grateful to be alive and attributed much of their success to the skilled providers who had cared for them.

Summary

Meeting and spending even the short amount of time I had with participants and their significant others, I was able to learn a great deal about their burn injuries and how their burn-related experiences had been incorporated into their life stories that they shared with me. As I analyzed data obtained through my clinical observations, interviews, reflexivity journal, and field notes, I was able to identify three distinct yet inter-related themes: “How it Feels” to be a burn survivor, “Somehow, I’m Still Me” after everything the participants had been through, “Yet, I’m
Better” and have grown from the experiences associated with being burned. Sib-themes within each of the themes emerged through data analysis as being most prominent between transcripts and provided a deeper representation of how these eight burn survivors experienced major burn injuries and their recovery.

Through qualitative, phenomenological analysis, participants and their significant others provided me the opportunity to collect and examine details about their burn events, journey toward recovery, and how their individual and yet similar experiences were then woven into their life stories that are shared with others. Each burn survivor participant had accomplished so much more than merely to sustain life in the face of burn injuries, they were all well on their way to their best outcome as they journeyed toward recovery from their burn injuries, and were leading productive lives with supportive social relationships within their communities.
CHAPTER FIVE
SUMMARY, CONCLUSIONS, DISCUSSION, AND RECOMMENDATIONS

This chapter provides an overview of the outcomes of the research. Through data analysis of participant and “significant other” interview transcripts, my field log and reflexivity journal, and my pilot study, it was found that Resilience Theory offers the most inclusive theoretical framework to describe and explain how my participants experience their burn injuries and recovery, and health as well as how they were able to rebound after major burn injuries.

Purpose of the Study

The purpose of this study is to explore the psychological, emotional, spiritual, environmental, social, and vocational experiences of survival and recovery from the phenomenon of traumatic thermal burn injury and how survivors make meaning for these experiences within their life stories. Through their words we may gain an understanding of how they navigate their journey toward survival, recovery, and health/wellness following major thermal burn injury and the factors they attribute to their current health. In addition, this study will explore how survivors’ home communities may impact long-term health outcomes and quality of life.

Summary of the Study

I designed this qualitative study to explore the phenomena of burn injury and how young and middle adults make meaning for their survival and their path toward recovery. I hoped to find out how participants experienced their health and quality of life after major burn injuries. In an effort to triangulate data for the study, I included “significant others,” when available, as they had lived through the burn experience with the participants whom they accompanied to the
interviews. As I began this study, I imagined many of the burn-related experiences participants had woven within their life stories would influence their personal health with the same impact as possibly where they lived or some significant rite of passage. I also wondered if there were common characteristics between participants that might be important to survival and recovery after major burn injuries. And most of all, I wondered if those personal factors could be found within a theoretical framework that could explain important assets/strengths that were used by participants to support effective adaptation and resilience within the journey toward recovery for future burn patients. The questions that I hoped to answer with this research were:

1. What is the burn experience for young and middle adults living in the Midwestern region of the United States?

2. How do young and middle adult burn survivors living in the Midwestern United States make meaning for their major burn-related recovery and health?

3. How do the structural networks/communities of young and middle adult burn survivors impact their burn-related recovery, health/wellness, and quality of life?

I interviewed eight burn survivors one time, asking questions about their quality of life and six dimensions of health: physical, emotional, psychological, spiritual, environmental, and vocational. Four “significant others” were also interviewed one time and questions asked were focused on the survivors’ experiences. Interviews with participants and “significant others” were separate and lasted approximately 30-45 minutes each. For convenience’ sake, when participants brought “significant others” to be interviewed, they were interviewed in the presence of each other rather than at separate times or in separate places. All twelve interviews were conducted over a four week period. Four of the male participants were married at the time of their burn
injuries and three wives were included as “significant others,” the fourth significant other was a participant’s mother.

Seven of the participants were men and one a woman ranging in age from 37 to 78 years at the time of interviews. Two participants were burned when in their twenties, one in his thirties, two in their forties, two in their fifties, and one was burned in his early sixties. All eight participants were Caucasian and had sustained between 20% and 98% TBSA thermal burns. Three participants were burned while on the job and five were burned while engaged in activities around their homes. The types of heat sources that caused participants’ injuries were scalding water, an electrical arc, and fire fueled by accelerants (LP gas, oil, and gasoline). All eight participants were living in the central Illinois catchment area for SIU School of Medicine/Memorial Medical Center in Springfield at the time of their injuries as well as the time they were interviewed. Two participants lived in the two larger cities in the region (pop. 76,000 to 116,000) and the other six in small, rural communities (pop. < 7,000) (U.S. Census Bureau, 2012).

Each of the participants had experienced the life phases of early and middle adulthood as burn survivors. The developmental criterion for the study was intended to uncover personal factors that promote effective adaptation and recovery for early and middle adults whose life crisis are believed to be establishing intimate relationships and fostering careers, respectively. I chose this age parameter because I wondered how burn injuries that occur in adulthood impact participants’ interpersonal relationships as well as their employment history. Through semi-structured interview questions, I was able to explore how participants perceived their burn-related experiences that impacted their health and how those experiences were woven into their life stories that were then shared with me.
Seven of the eight burn survivors had participated in at least one burn support activity however, Sid had not. Sid had contact with other burn survivors through both his family and the community, including the man who had survived the same oil field explosion. He was included within the sample as his burns were the most severe and his story needed to be heard as it reinforces the need for supportive services beyond the burn unit in the most effective capacity based on the strengths and needs of the patient.

After organizing data sources, I engaged in “reductionist” data analysis (Rudestam & Newton, 2007) of all twelve verbatim transcripts, field notes, and my reflexivity journal. I was able to identify three consistent themes among data sources including: “How it Feels” to be burned, “Somehow, I’m the Same” on the inside after all I’ve been through, and “Yet, I’m Better” as participants felt they had grown as a result of their burn injuries. Within each of these themes are sub-themes that depict important factors of burn recovery, adaptation, and resilience that were shared by participants, illuminating a deeper understanding of how these early and middle adults living in the Midwestern United States experienced survival following major burn injuries and their journey toward recovery.

I hadn’t given any thought to the race or gender for my participants but rather welcomed the eight participants who volunteered and were aligned with the parameters of this research that included age and percentage of TBSA thermal burns. The initial question I asked of participants was how their burn injuries occurred. This question was important because I believed their “story” would expose their identification as burn survivors as it had mine. These stories often become polished over the years and by the number of times it had been told to children who asked and strangers in an effort to break the ice. I would even intentionally work my “story” into
conversation with a new person who I believed would be in my life for a while as a means to dispel any curiosity on their part, real or imagined on my part.

After each participant shared with me what their burn injuries involved, I then focused my questions on how it felt to be burned and how the experiences had impacted their dimensions of health. Many of the interview questions appeared to be a surprise for participants as the questions attempted to uncover factors associated with their injuries that were not part of the story they were accustomed to sharing and required them to consider other aspects of their burn-related experiences that were unexamined parts of their burn injury stories.

Conclusions

Based on the findings of the primary study and pilot study, Resilience theory offers the most inclusive theoretical framework to explain how participants were able to incorporate their burn survivor status into their life story and recapture many of their roles following major burn injuries. Utilizing the constructs within Resilience theory including social competence, problem solving, autonomy, and sense of purpose provide, there is an opportunity to organize sub-themes found through data analysis, believed to reflect innate resilient strengths that serve as protective factors in the face of adversity.

Within the construct of social competence, participants exhibited important innate resilient strengths of empathy, resourcefulness, and compassion which are believed to be important protective factors provided through social relationships. “Social competence includes the characteristics, skills, and attitudes essential to forming relationships and positive attachments with others” (Benard, 2004, p. 15). All of the study participants believed their interpersonal relationships were better than before their burn injuries occurred. There was a shared belief among the group that they had grown in their sensitivity to the needs of others and
were grateful for their families and the many supportive friends and neighbors from their communities who were there in their time of need. Each participant’s empathy toward the needs of burn patients who follow them influenced their decision to volunteer for this study. Their goals were simply stated, they wanted to help people and believed that by sharing their stories, they might help burn survivors in the future.

Within the construct of problem solving, participants reflected on their abilities for planning and resourcefulness. It is believed that general problem solving skills include the ability to: be motivated to approach and solve problems; accurately identify a problem; generate an appropriate response to the problem; consider the consequences of possible solutions; choose the best solution to the problem; and the ability to implement that solution (Kumpher, 1999). The men in the sample displayed the ability to make plans for how they could complete tasks as they healed, approaching each challenge as a means to increase their strength and regain their autonomy. Beth was able to identify problems however had difficulty generating appropriate responses to her problems which left her in a more dependent state.

Participants exhibited initiative, self-efficacy and mastery, adaptive distancing and resistance, and humor which are consistent factors within autonomy. “Autonomy involves the ability to act independently and to feel a sense of control over one’s environment” (Benard, 2004, p. 20). Each of the men in the sample worked diligently to increase their independence through their own efforts. They participated in difficult physical therapy that tested their strength, stamina, endurance, and patience. Yet they didn’t give up on these difficult tasks because of their confidence in their ability to succeed. The men were able to distance themselves from social stigma and resisted the tendency burn survivors have of adopting a negative self-image. All of the participants used humor to aid in their journey toward recovery. They were
able to laugh at themselves and many of their burn-related experiences that others might have
had difficulty with, given the serious nature of their injuries. Their humor carried them through
many of their difficult times as they focused on laughter rather than tears.

Participants exhibited a sense of purpose, another important construct within Resilience
theory. A sense of purpose includes not only the belief in a positive future, but also possessing a
sense of meaning within one’s life (Benard, 2004). The assets most apparent among participants
were goal-directedness, creativity, optimism, and faith/spirituality. They each displayed a sense
of optimism in the face of crisis and were supported by their faith in prayer and their spirituality.
Of all of the protective factors, spirituality was considered vital within the journey toward
recovery and health for all of the participants, and each participant believed they had grown
spiritually since their burn injuries. Participants’ church families played an important role in
each of their lives prior to their burn injuries and participant commitment toward their church
families grew in strength following their burn injuries. Prayer was believed to have been
substantially responsible for positive outcomes for each of the participants as they reflected on
how many people had been praying for them. These prayers were offered up by loved ones,
friends, and even strangers by virtue of prayer chains. For those participants who sustained
massive burn injuries, their survival was attributed to God and his ability to intervene on their
behalf, increasing their sense of wonder over God’s power and benevolence.

After interviewing adult burn survivors, I developed a greater appreciation for how
participants’ rural communities work and the protective factor provided by their social networks.
The acceptance and support provided by community members was not a gift given to participants
as I had previously imagined. The relationships among participants who lived in a small, rural
communities and their neighbors were reciprocal in nature and built over a lifetime. My
participants did not just live in their small, rural communities. They were “from” their small rural
communities. The responses of the community members reminded me of western settlers who
circled their wagons when they were in danger. Participants’ friends and neighbors came
together in response to burn injuries that had almost taken one of their own, and did what was
needed to be done to return their communities to the state of equilibrium that was disturbed by
the crisis. What I came to realize as the themes emerged through data analysis was that there was
an important sense of community that had been established well before to Jake, Matt, Steve,
Sanders, Trooper, and Sid’s burn injuries and represented sometimes multiple generations of
community acceptance and participation. It might not have been the participant’s investment in
the community per se; the relationship might have been established by their parents or even
grandparents who had been part of that community. It was almost like “money in the bank” as
their friends and neighbors stepped in to make sure that responsibilities of the burn
patient/participant were not left undone, whether it was to bring in the corn and beans, put a
house back together, or just to check in on a family. This community support was provided to
participants through their healing period and continued into their journey toward recovery,
providing a protective factor that comes from knowing that one is not alone, but a part of
something much bigger. The six participants from small, rural communities within the catchment
area for the MMC burn unit received a greater level of community based social support than the
Beth and Dan who were city dwellers.

All of the study participants and their “significant others” were grateful. Some were
grateful to be alive and for all of the kind things family, friends, and neighbors had done to help
them in their time of need. They were grateful for the ability to walk, feel the rain on their
heads, and the sun on their faces. They were grateful to be able finally take that fishing trip, to
ride a motorcycle, travel to visit loved ones, jump out of an airplane, return to work, or run in a marathon. But most of all, they were grateful for the doctors who put them back together after their burn events. They were grateful for the generosity, warmth, and skill of the nurses who had seen them at their worst and were kind to them anyway. I think they will always be grateful for the nurses.

Discussion

I initially began this project to identify the strengths that might be important to survival and recovery from major burn injuries. I directed my questions in a way that participants were able to recognize their strengths and to take pride in their accomplishments and successes. This led to the usefulness of resilience theory as a framework that best suits the identification of resources necessary to recover from this kind of crisis. This study was able to identify positive assets within data that were reflective of process resilience. Participants spoke of the many factors that influenced their healing and journey toward recovery as being consistent with resilient “buffering effects” (Cohn & Syme, 1985, p. 6) or protective factors. Of those protective factors described by participants, social relationships were very important to their recovery status. They each attributed much of their successes as being directly tied to the reciprocal relationships within their social networks. While participants were hospitalized community members carried many of the participants’ home responsibilities. In the same manner as how Jake, Steve, and Matt’s neighbors brought in their crops, checked on their families, and reconstructed Matt’s home, the support was continued after they returned home. The investment of social support may have been evident when Matt’s friends from AA picked him up to take him to physical therapy and then to lunch. AA is a support organization in which the giver receives and the receiver gives support within the group. This brings to the surface the
importance of peer support anyone who is challenged and that includes burn survivors. With cutbacks, limited budgets, and broadened job descriptions, support groups seem to be the first thing cut.

Return to normalcy was an important participant goal, and appeared to be directly tied to productive activities. Dan described his return to college as returning to a sense of normalcy despite his physical limitations. Beth spoke of how she had tried to go back to school to study the laws that protected renters, attempting to recapture the activity level and direction she had prior to her burn injuries. Her husband had even tried to complete her job responsibilities as a Certified Nurses’ Assistant while she convalesced at home in an effort for her to maintain her employment. Each participant was encouraged by family, friends and neighbors who allowed them the necessary time needed as they recovered their strength and established their new levels of functioning as burn survivors. But the goal for many of the participants within this group was to return to work. Return to work was directly tied to Dan, Steve, Matt, and Sid’s self-esteem and quality of life (Osterm, Kildal, & Ekselius, 2010). Both Sid and Trooper, who sustained massive burn injuries, were accepted by their communities as being unable to return to work, however Sid continued to be challenged by his inability to work based on his normative views that family men work. Within burn care literature, severity of injuries is deemed the most important variable impacting RTW (Esselman, et al., 2007; Fauerbach, et al., 2001; Oster, Kildal, & Ekselius, 2010). Unlike a previous study investigating issues associated with return to work (Osterm, Kildal, & Ekselius, 2010), there was little connection between education and return to work as Dan was the only college graduate within this participant group. The other participants were farmers and laborers. They were people who relied on their strength and stamina to do their jobs. Matt, Steve, Sanders, and Dan were all able to return to gainful
employment following their burn injuries. Each of them had sustained greater than 30 percent TBSA burns.

Each participant spoke of physical limitations brought about by their burn injuries including pain, sensitivity to weather, contractures, fragile scar tissue and grafts, and in one participant’s case, loss of several fingers. These limitations did not hinder participants from productive activities. Beth, who did not return to work, sustained the lowest TBSA burns within the participant group which is consistent with studies indicating that survivors with < 20% TBSA are less likely to return to work than those with more severe burn injuries (Esselman, et al., 2007; Fauerbach, et al., 2001; Oster, Kildal, & Ekselius, 2010).

When Jake, Steve, Matt, Sanders, and Sid returned to their homes, they were embraced by the residents of their small, rural communities, as the people they had always been. There was no apparent stigma attached their appearance or concern for how the accidents occurred. The men described relatively smooth transitions from hospital to home as family and community members had remained involved in their lives, even when they were far away at Memorial Medical Center in Springfield. The natural return of participants to their home communities allowed them to regain many of their important social roles which they describe as having a positive impact on their self-esteem, self-efficacy, and quality of life. Trooper, who was not able to return to his previous house returned to the small town in which his family had lived when he was growing up. Once he settled into his new home, the community welcomed him like an old friend who had been gone for a long time but finally returned. The reciprocal relationships within participants’ home communities had been built over a lifetime. Previous researchers speak to the importance of the reciprocity that is found in social relationships (Fine, 1991) and that the reciprocity within the relationships that is present was likely established long before the burn
injuries occurred (Badger & Royse, 2010; Moi, Vindenes, & Gjengedal, 2008). There are vital assets associated with one’s social group or community as these people proved a sustaining force for burn survivors (Cohn & Syme, 1985).

One of the greatest differences between Beth and the men within the participant sample is that she was unable to return to a level of independent functioning within her social network. The men all regained their autonomy and independence as they healed, which was a natural progression as they returned to work or, school, and other productive activities. Participants’ social networks provided the continuity that was required for them to remember who they were, recapturing the old aspects of themselves and discovering the new. Over time, they were able to absorb their survivorship and growth into their life stories.

Among the experiences of participants, there were aspects of growth they tied to their burn events and healing. It might have been increased patience with others or feelings of empathy where it hadn’t been before. Spirituality was the one of the most profound areas in which participants expressed their growth. They described the importance of prayer in their survival and recovery, and credited their relationship with God as being the saving grace in their lives. Previous research describes the importance of recognizing spirituality within the healing process. Spirituality serves as a coping mechanism, as survivors credit their religious faith and God for their survival and level of recovery from their burn injuries (Arnoldo, Hunt, Burris, Wilkerson, & Purdue, 2006). Jake, Matt, and Beth became more involved in their church families as they healed and moved toward recovery. Sid and Trooper felt their belief in God was strengthened as a result of their burn injuries. This sense of meaning described by participants is supported by research indicting the belief that there is the opportunity to grow within crisis, and define it is post-traumatic growth (PTG) (Askay & Magyar-Russell, 2009; Rosenbach &
Renneberg, 2008). Interestingly, while Askay & Magyar-Russell (2009) found a relationship between survivor’s level of education and interpersonal growth, the results of this research did not support their findings.

The framework within the interviews questions as based on the seven dimensions of health. The difference in my focus was not on participants’ deficits in health, but rather their strengths as describe through their stories. The seven dimensions of health include: physical, mental, social, spiritual, environmental, emotion (Greenberg, 1985) and vocational (Eberst, 1984). Utilizing this framework of health, I was able to explore an ecological perspective of participants’ survival and path to recovery. This model allowed participant responses to provide a clearer picture of both their intrapersonal, interpersonal, and environmental factors that have influenced their health (McLeroy, Bibeau, Steckler, & Glanz, 1988).

All of the men in the participant sample reported very positive physical health in spite of any previous serious illnesses such as Jake, who was a cancer survivor. Their physical health was directly tied to being able to regain their ability to work. For Matt and Steve, success meant returning to their previous jobs. For Dan, it was feeling physically fit enough to run in a marathon or jump out of an airplane. Beth reported her physical health as poor however, her thoughts of physical health did not encompass her burns, but rather other chronic health conditions such as diabetes, obesity, a thyroid disorder, and two episodes of cancer.

When participants addressed questions about their social health, the men were able to speak to the many people in their lives who had been supportive and had made their path to recovery much easier. Spiritual attributes were the area of health that was the most profound within the findings of this study. All of the participants felt their spiritual health was great and that their burn experiences had only strengthened that dimension of their health. None of the
participants felt their environmental health had been compromised by their burn injuries. Even Trooper, who was discharged to a nursing home and then to a new home purchased in his home town, did not feel as if his environment created any problems. With the exception of Beth, participants within the sample were able to regain their mobility and stated they never really felt the inability to move freely within their environment. Matt was not able to return home however that did not seem to make any differences to his sense of environmental health.

Each of the participants spoke of periods of depression during their hospitalization however the men reported that their feelings of anxiety and sadness faded as they regained their independence. This may have been the issue with Beth as she became increasingly dependent on her family of origin within her recovery. The men informed me they were able to recover from any problems within their emotional health as they healed and their autonomy returned. There was a connection between health and quality of life for participants in this research. The men who reported their health as positive also reported their quality of life as being positive. There is some evidence that those individuals that had a previous history with mental health conditions were more likely to experience emotional difficulties following a crisis.

The seven male study participants believed their overall health and quality of life were good regardless of any co-morbid conditions or the severity of their burn injuries. These findings are supported by current literature (Leblebici, Adam, Bagis, Tarim, Noyan, Akman, Haveral, 2006; Moi & Gjengedal, 2008) in that the men within this study who sustained the most severe burn injuries (33% to 98%) reported their health and quality of life as great or good while the Beth who sustained the least severe (20%) reported her health and quality of life as poor (Leblebici, Adam, Bagis, Tarim, Noyan, Akman, Haveral, 2006; Moi & Gjengedal, 2008). The men’s positive outlook on their seven dimensions of health may have been supported by their
optimism which was not apparent with Beth. However, to be fair to Beth, there were mitigating factors that might have influenced her pessimism, such as a limited social support system, living in a city with a population over 70,000, lack of self-efficacy, depression, and inability to distance herself from her negative appraisal of her burned feet.

As burn care research evolved, recognition and utilization of qualitative designs as opposed to primary reliance on quantitative measures increased. Some qualitative researchers turned to narrative and case study paradigms, attempting to reflect how patients perceive their physical healing, social reintegration, and reconstruction of self (Bernstein, O’Connell, & Chedekel, 1992; Lau & van Niekerk, 2011; Moi & Gjenedal, 2008; Moi, Vindenes, & Gjenedal, 2008; Morse & Carter, 1995; Morse & Carter, 1995) in relation to their new “burn identity” (Lau & van Niekerk, 2011, p. 1166). They broke away from traditional theoretical models and struck out to establish new models to explain how burn survivors make meaning for their injuries. Yet, there has been little effort within the burn research to find a more encompassing theoretical framework on which to identify the innate strengths found within survivors of major burn injuries. The participants in the research not only survived their injuries, the men within the sample were able to thrive within their journey toward recovery.

The findings of this research lend support for Resilience theory to be that inclusive theory that describes the strengths and assets participants of this study described as being supportive of their survival and journey toward recovery. The findings also indicate the inter-related nature of health and quality of life with in this group of participants.
Limitations

There were a variety of limitations within this study that could limit transferability. They include:

1. The participant sample was dependent on those burn survivors who made themselves available for this research. There was a smaller sample than I had hoped for and might have been different had I included another hospital as a recruitment center.

2. Women were underrepresented in the study sample. This was not intentional but was based solely on those burn survivors who made themselves available.

3. All of the participants within this study were Caucasian, providing limited variability for race, sexual orientation, religion, or culture. I had hoped to include an urban burn center which would have likely afforded greater variability within the

4. The findings of this study may be unique to the Midwestern rural communities of central Illinois but may be possibly applicable to rural catchment areas of regional medical centers.

5. I have been accused of volunteer bias, and that may be true. I liked each and every one of participants for their strengths and courage, focusing on their assets rather than deficits.

Recommendations for Public Health and Health Educators

The role of public health is to promote and protect the health and wellbeing of the nation’s residents, supporting positive, health-related quality of life (HHS, 2009). Burn injuries that result in disability due to disfigurement and/or loss of function have been found to hamper survivors’ access to important elements within their environment that promote quality of life, including many health-related benefits that may be more readily available to the general
population (HealthyPeople, 2012). To compensate for at least some of these challenges, additional protections are extended to survivors of disfiguring burn injury under the Americans with Disabilities Act of 1990 (PL 101-336) in an effort to equalize public access and consideration (ADA, 2009). Additional federal recognition for the health and wellbeing of burn survivors can be found within the goals of Healthy People 2020. Outlined in the leading health indicators of the plan, attention is drawn to an ongoing need to support the health and wellbeing of those living with disabling conditions, supporting inclusion within all facets of society enjoyed by the general population (HealthyPeople, 2012).

When I began this study, almost everyone I talked to couldn’t understand how burn survivors could make up a large enough group to consider them a population at risk, however I disagree. Approximately 1.25 million Americans are burned each year accounting for approximately 1% of the U.S. population on a yearly basis (Muller, Pegg, & Rule, 2001). To offer some perspective on the incidence rate of burn injuries, consider that the Jewish population in the United States is estimated at approximately 2% (jewishvirtuallibrary.org). In addition, the life time financial burden of medical costs and loss of productivity associated with burn injuries in the US for the year 2000 was estimated at over $7.5 billion (Corso, Finkelstein, Miller, Fiebelkorn, & Zaloshnja, 2006). The public health burden of major thermal burn injury is increased as the number of wounded combat veterans return Iraq and Afghanistan with major thermal burn injuries to faces and hands as a result of the incendiary types of weaponry being used in those regions (Cancio, Horvath, Barillo, Kopchinski, Charter, Montalvo, Buescher, Brengman, Brandt, & Holcomb, 2005; Hoge, Castro, Messer, McGurk, Cotting, & Koffman, 2004; Mora, Ritenour, Wade, Holcomb, Blackbourne, & Gaylord, 2009).
What I have discovered since beginning this study and a review of the current burn care literature is that burn survivors make up an important segment of the population with chronic health care needs but no specific, theory-driven interventions to help them reach their best possible outcomes. This includes when they are being treated on the unit as well as post-discharge. The statistics presented provide incentive to develop and provide supportive interventions for burn patients who do not know how to access their innate resilient protective factors in a successful manner.

Article V of the Health Education Code of Ethics provides for what isn’t known about the health of a population of interest and calls on health educators to take responsibility for research that may contribute to the health of the populations we serve (NCHEC, 2008). Recognition of this growing population of burn survivors is the first step that should be taken by Health Educators. We have an ethical responsibility to contribute to the health of the burn survivor population through research and evaluation activities that will build and promote supportive interventions that may in turn build and support the many dimensions of health for the burn survivor community.

Recommendations for Future Research

One of the values of qualitative research is that it provides the opportunity to uncover important constructs that can then lead to empirical testing. There are currently several resilience scales that have been utilized with other chronic illnesses and warrant being utilized with the burn survivor population. The results of this study and others like it may provide enough evidence that those in the hard sciences who only believe in the truths that are derived through quantitative rigor might understand the value of understanding the uniqueness and resilience of individuals as being important to surgical and medical outcomes.
Summary

I’ve learned something very important from participants of both this primary study and my pilot study that I had never been able to put my finger on within my own recovery journey. The term “recovery” for burn survivors takes on a different meaning because burn injuries are not like a broken leg that heals. Participants taught me that recovery of the physical form wasn’t possible for burn survivors because of the irreparable damage done to the body. Their best hope was to regain the highest level of functioning with the least amount of times they would have to return to the hospital, and risk the potential of having to “start over.”

Recovery of the spirit is the journey’s real destination and of greatest importance to the participants of this primary study as well as my pilot study. I have come to that imagine adoption of the title “burn survivor” must be similar to a cancer survivor who is forever changed and adopts the moniker of “survivor” as a badge of courage. But there is a continuum of need that might be different for each burn patient and those needs could be deciphered through discovery of what resilient protective factors the patient has exhibited in the past. Factors identified within this study indicate the resilient factors that were most important in participants’ journey toward recovery were social support, goal directedness and self-efficacy, optimism, use of humor, spirituality, and insight. Discovery of important protective factors in burn recovery may then be accomplished through face to face interviews with the patient and their “significant others” to build an understanding of recurrent themes that would pave the way for empirical tools may then be utilized for quantitative exploration and interventions that will promote the best possible outcomes for burn survivors in the future.
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Interview questions for Burn Survivor participants – Appendix F

I. Opening:

1. Please share your age and your current living situation (Prompt: If living with others, who are you living with? If not, have you had any difficulty living alone since your injuries? Are your burns a factor in your current living situation?)

The burn experience:

3. Can you think back to your burn injury? Can you tell me what happened? (Prompts: What was it like for you?)

4. Have your burn injuries impacted any important aspects of your life (thoughts, feelings, jobs, goals, activities, relationships, hopes for the future)? (Prompts: If no, how do you think you were able to maintain these aspects of your life? If yes, how have your burn injuries affected those aspects of your life? What was that like?)

5. How would you describe quality of life? (Prompts: Has your quality of life been affected by your burn injury? If yes, how it’s different now?)

6. How would you describe your health (physical; spiritual; environmental; emotional; social; and vocational) before your burn injury? How about now?

Psycho-social changes:

7. Are you different now than you were before your burn injury? (If yes, could you tell me how you’ve changed (thoughts, feelings, jobs, goals, activities, relationships)? (If no, move on to next question).

8. How would you describe your community (size, level of connectedness, availability of instrumental and tangible support)? (Prompts: How did people in your community respond to your burn injuries? Were they helpful? How did that feel?)

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9. How do people who know you respond to your burn scars? How about strangers?
   (Prompts: How does it feel if people stare or ask you about your burns? How do you feel about their reactions?)

10. How does it feel when you are with other people who have been burned?

Advice for other burned patients and survivors:

11. If you could tell a newly burned person how to get through their hospitalization and recovery, what would you tell them? (Prompts: Are these things you actually did when going through your hospitalization and recovery? If no, how did you learn these helpful things? If yes, how did you know to do those things?)

Closing:

12. How are you feeling now after talking about your burn injuries and recovery? (If feeling badly: Would it be helpful to talk to someone about these feelings? If not feeling badly: Can you describe how it feels to have gotten to this place in your recovery?)

*Interview questions adapted from my pilot study and Holaday & McPhearson, 1997
II. Interview Questions for Significant Other Participants: Appendix G

Opening

1. Please share age, your current living situation, and your association to the burn survivor. Are you living with the burn survivor? (If yes, are his/her burns a factor in their current living situation? If no, did your significant other have any difficulty living alone since his/her injuries?)

The burn experience:

3. Can you think back to when your significant other’s burn injury happened? (Prompts: What was it like for him/her? Was anyone else injured with your significant other?)

4. Have your significant other’s burn injuries changed any important aspects of his/her life (thoughts, feelings, jobs, goals, activities, relationships)? (Prompts: If no: What do you attribute to his/her success? If yes: How have your significant other’s burn injuries affected those important parts of his/her life?)

5. Were there any problems related to your significant other’s burn injuries that were hard for him/her to solve? (If no: How did he/she learn to cope with burn-related problems? If yes: How did he/she solve those problems).

6. How would you describe the burn survivor’s quality of life? (Prompt: Has your significant other’s burn injury affected his/her quality of life? If yes: Can you think about how it’s different now? How about yours? Is it better today than before he/she was burned?)

7. How would you describe your significant other’s health (physical; spiritual; environmental; emotional; social; and vocational) before his/her burns? How about now?
Psycho-social changes:

8. Please tell me about the community that your significant other lives in. How would you describe his/her community (size, level of connectedness, availability of instrumental and tangible support)? How did important members in the community respond to his/her burn injuries?

9. How do people who know your significant other respond to her/his burn scars? How about strangers? (How does it feel for him/her?)

Advice for other burned patients and survivors:

10. If you could tell a newly burned person how to get through their hospitalization and recovery, what would you tell them? Are these things you actually did? (If no, how did you learn these helpful things? If yes, how did you know to do those things?)

Closing:

11. How are you feeling now after talking about your significant other’s burn injuries and recovery? (If feeling badly: Would it be helpful to talk to someone about these feelings? If not feeling badly: Can you describe how it feels to have gotten to this place in your recovery?)

*Interview questions adapted from my pilot study and Holaday & McPhearson, 1997