Risk versus resilience: an exploratory study of factors influencing the development of posttraumatic stress symptoms in pediatric burn patients

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RISK VERSUS RESILIENCE: AN EXPLORATORY STUDY OF FACTORS INFLUENCING THE DEVELOPMENT OF POSTTRAUMATIC STRESS SYMPTOMS IN PEDIATRIC BURN PATIENTS

by

Sarah Elizabeth Powers

An Abstract

Of a thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Psychological and Quantitative Foundations (School Psychology) in the Graduate College of The University of Iowa

December 2011

Thesis Supervisors: Professor Stewart Ehly Adjunct Assistant Professor Tammy Wilgenbusch
ABSTRACT

Children account for approximately 34% of the burn-injured population in the United States and are particularly at risk for developing posttraumatic stress disorder (PTSD) or other significant psychopathology (i.e., behavioral and attentional difficulties, acute stress, depression, anxiety, phobias, dissociative symptoms, and enuresis). There is a significant risk that quality of life (QOL) can have a negative impact on children who have sustained a burn injury, particularly within the domain of social functioning. Specifically, children who meet the criteria for PTSD following a burn injury are at an increased risk of experiencing impairment in overall QOL. However, there remains significant evidence that a substantial portion of children exhibit satisfactory QOL outcomes following a burn injury at a level comparable to their noninjured peers. This positive outcome may be attributed to the child’s level of resiliency—the protective factors that positively influence their ability to adjust and move forward following a traumatic event.

Research on risk and resiliency of posttraumatic stress symptoms (PTSS) in pediatric burn survivors is limited. For psychological assessment and burn treatment to be successful, it is important to understand the resilient qualities that are present in children who experience positive post-burn-injury outcomes. By focusing on a child’s mental health strengths and by building his or her resilience, a health professional may prevent or lessen the child’s adjustment difficulty or psychopathological symptoms.

Thus, the primary purpose of this study was to identify the relation between pediatric burn injury, demographic variables, resilience and QOL outcome with regard to PTSS. Demographic information (e.g., gender, age, household income, and diagnoses) and burn injury characteristics (e.g., age at time of burn, total body surface area injured, number or days spent in the hospital, and number of surgeries) were considered with regard to PTSS, resiliency, and QOL outcome. Further analysis efforts compared results
from the Resiliency Scales for Children and Adolescents (RSCA) with scores obtained from the University of California at Los Angeles Posttraumatic Stress Reaction Index for Diagnostic and Statistical Manual—Fourth Edition (UCLA PTSD Reaction Index for DSM-IV; Reaction Index). Identical analyses were performed regarding the RSCA and the Pediatric Quality of Life Inventory, Version 4.0 (PedsQL 4.0).

Analyses indicated a significant relation between PTSS severity and resilience, with positive resilience outcomes correlated to lower levels of PTSS severity. Further, a significant relation was found between QOL and PTSS, with positive QOL functioning related to lower levels of PTSS. Finally, a significant relation was found between resilience and QOL: Participants who endorse higher levels of resilience demonstrate better QOL outcomes. Overall, demographic information and burn injury characteristics did not significantly affect results regarding PTSS severity. Clinical implications and future areas of research are discussed.

Abstract Approved: ____________________________
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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

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has been approved by the Examining Committee for the thesis requirement for the Doctor of Philosophy degree in Psychological and Quantitative Foundations (School Psychology) at the December 2011 graduation.

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Scott Lindgren
In loving memory of my grandparents
ACKNOWLEDGMENTS

Life is a product of the choices that we have made. After completing my first day of an undergraduate Introduction to Psychology course, I decided that graduate education was going to be in my future. At the time of my decision, I knew that there would be years of hard work ahead of me, and I knew that I would survive with a little help from my friends and family.

Throughout my graduate career, I have leaned on family and friends for support and encouragement as I made my way through years of education and sacrifice. Each of them has been instrumental in the completion of my degree, and to all of them I give my gratitude.

To my husband, Josh, you put your dreams on hold so I could pursue mine; I owe you so much. You have selflessly provided our family with the support that we needed to get to this point. I love you for all you have done.

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To my friends and fellow graduate student colleagues, each of you has made this experience immensely enjoyable, and I cherish the lifelong friendships that I have made throughout my journey. Graduate school changes a person; my confidence, self-sufficiency, and enthusiasm for my profession have grown tremendously throughout these past years of growth and self-reflection. I have taken a piece of each of you with me as I have transitioned into adulthood and I will miss all of you.
To my mentors, supervisors and committee members, thank you for laying the foundation of my knowledge and providing the praise and criticism that I needed to grow into a competent professional. To Dr. Amy Conrad, thank you for your assistance with data analysis. To Patricia, thank you for helping me in the editing process with this project. Your work and dedication is so appreciated.

To the children and their parents who have invited me into their families for a brief while, thank you for allowing me to grow professionally and personally through my work with you. You truly inspire me.

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CHAPTER I

INTRODUCTION

How do we recover from the curve balls that life throws our way? Why do some of us rebound, recover, and even thrive after a traumatic event, while others spiral downward and seem never to be the same again? What personal factors contribute to our ability or inability to move onward and upward after experiencing life’s hard knocks?

Resilience refers to the protective factors that allow a person to cope with various types of adversity (Prince-Embury & Courville, 2008). Resilience was first conceptualized as protective factors present in individuals who thrived during hardship in comparison to those who struggled (Garmezy, Masten, & Tellegen, 1984; Luthar, 1991; Werner & Smith, 1982). Early research, in identifying resilient factors in children who performed well in contexts of adversity, argued that the development of interventions would be strengthened (Masten, 2001). Rather than define resilience as a remarkable phenomenon present in these invincible children, Masten conceptualized it as a normative function that is an inherently human process, an adaptational and protective system present in most of us. If this system is protected, humans can generally recover from a hardship; however, if the system is impaired and/or if environmental hazards are present and prolonged, developmental problems are more likely to occur (Masten, 2001).

One of the eight foundational competencies for school psychology training proposed by the National Association of School Psychology (NASP; 2006), resilience is a crucial skill for school psychologists to consider when they create and implement prevention and intervention programs for children. In the Blueprint for School Psychology, the role that resiliency plays in a child’s “coping with daily stressors and setbacks” is discussed in the first outcome—“Improve competencies for all children and youth” (NASP, 2006, p. 13).

For resilience to be assessed, a significant threat to typical development must occur; individuals who have not encountered adversity cannot be described as resilient (Masten, 2001). Risk factors that have been studied in relation to resiliency include parental variables such as having a parent with mental illness, to environmental factors such as low socioeconomic status, to traumatic variables such as exposure to violence or maltreatment (Masten & Garmezy, 1985). The current study will investigate the relation between burn injury, demographic variables, quality of life (QOL) and resilience in relation to posttraumatic stress symptoms (PTSS). A significant portion of the literature has focused on psychopathology in children with burn injuries; the current study aims to provide a view of children who experience difficulty following a burn and those who demonstrate resilient qualities. Identification of the inherent differences that exist within a spectrum of PTSS in children is important to obtain a realistic, objective representation of pediatric burn patient outcomes. By focusing on a child’s mental health strengths and by building his or her resilience, a health professional may prevent or lessen the child’s adjustment difficulty or psychopathological symptoms (Holaday & McPhearson, 1997). Clinical implications of the current study will be further explained on the following pages.
Rationale

Arguably generalizable across psychological disciplines, resilience is a crucial area for psychologists to assess and strengthen within their clientele. Resilience is relevant to a child’s adjustment to daily setbacks (as indicated by NASP) in addition to infrequent and traumatizing stressful events. Little research has addressed the influence of the level of a child’s resilience on coping and stress management in relation to burn injury. Therefore, the current study aims to investigate the influence of resilience on a child’s experience of posttraumatic stress following a traumatic burn injury. A child’s level of resilience is useful to consider in planning accurate and individualized assessment, early intervention, and long-term treatment procedures following a pediatric burn injury. The following chapters will demonstrate how multiple disciplines and interested parties can benefit from the findings of the current study, including pediatric psychologists, medical staff, social work, parent/caregivers, and pediatric burn patients.

Children account for approximately 34% of the burn-injured population in the United States (National Center for Injury Prevention and Control, 2002; as cited in Stoddard, Saxe, et al., 2006). Children who have sustained a burn injury are particularly at risk for developing Posttraumatic Stress Disorder (PTSD; Stoddard, 1996). Approximately 30% of children meet the criteria for PTSD at some point within the six months after sustaining a burn injury (Saxe et al., 2005). Regarding young burned children, evidence has shown that a reduction in social smiling (related to characteristics of PTSD) occurs following a burn injury, along with reduced vocalizations related to the pain that accompanies a burn injury and subsequent treatment (Stoddard, Ronfeldt, et al., 2006). The pain that coincides with burn treatment contributes to the likelihood of a pediatric burn patient’s development of PTSS (Holaday & McPhearson, 1997).

There is currently a need for effective prevention of and treatment for PTSD in children (Saxe et al., 2001). By identifying characteristics of resilience that contribute to the avoidance of PTSD, physicians and psychologists can foster and increase these factors
in children who have experienced a burn injury. If left untreated, PTSD may affect a child’s brain development (Pynoos, Steinberg, Ornitz, & Goenjian, 1997) and lead to comorbid problems such as anxiety, substance abuse, and depression (Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Portnova, 2007). These long-term complications increase the importance of developing adequate assessment instruments, in addition to viable treatment options, for use with children who have experienced a burn injury.

**Purpose**

The purpose of the present study is to examine PTSS in children who have sustained a burn injury, in relation to resiliency factors and QOL outcome. Research on risk and resiliency of PTSS in pediatric burn survivors is limited. Existing research suggests that psychopathology in children who have sustained burns includes PTSD (Bronner et al., 2008), acute stress (Stoddard, Saxe, et al., 2006), separation anxiety, dissociative symptoms (Saxe et al., 2005), phobias, and enuresis (Stoddard, Norman, Murphy, & Beardslee, 1989). Research has suggested that a child’s QOL is likely to suffer following a burn injury, particularly in the domain of social functioning (Landoldt, Buehlmann, Maag, & Schiestl, 2009). Of particular interest to the current study, children who meet the criteria for PTSD following a burn injury are at an increased risk of experiencing impairment in overall QOL (Landoldt et al., 2009).

The goal of the current study was to develop a better understanding of both the protective factors (resilience) and vulnerabilities in children that affect the likelihood of acquiring or avoiding PTSS following a burn injury. According to Holaday and McPhearson (1997), resiliency in adults who have experienced a burn injury is a process, an ongoing battle that a burn patient wages to cope with their existence as an altered person, never to experience life in the manner it was lived pre-injury. Perhaps that process differs for pediatric patients; research is not definitive. In addition to investigating resilience in children in relation to PTSS, the current study was also
designed to examine the demographic variables and burn injury characteristics associated with a child’s experience of PTSS following a burn injury.

**Research Questions**

1. How are demographic variables (i.e., age, gender, household income, and diagnoses) related to a pediatric burn patient’s PTSS severity?

2. How are burn injury characteristics (i.e., age at burn, % TBSA, injury location, surgeries, days spent in hospital) related to a pediatric burn patient’s PTSS severity?

3. How are resilience factors (i.e., sense of mastery, sense of relatedness, and emotional reactivity) related to severity of PTSS?

4. How are QOL outcomes (i.e., physical and psychosocial functioning) related to symptom severity?

5. How are QOL outcomes (i.e., physical and psychosocial functioning) related to resilience?
CHAPTER II
REVIEW OF THE LITERATURE

Consequences of a burn injury are as varied as the circumstances surrounding the burn incident and the patient’s injury characteristics. Conflicting research describes positive and negative outcomes, without identifying a “standard” reaction or consequence of a burn injury (Holaday & McPhearson, 1997). Although outcome can be related to the visibility, severity, and repairability of damage to the patient’s body (Beuf, 1990; as cited in Holaday & McPhearson, 1997), altered appearance and loss of function are not always a predictor of long-term adjustment (Blakeney et al., 1993; Robert et al., 1999). Robert and colleagues examined self-esteem among adolescents who had sustained disfiguring burn scars, and found his sample to endorse similar or higher degrees of self-worth in comparison to their noninjured peers. Perhaps these startling findings are related to personal development that is enhanced by enduring and surviving a traumatic life event.

The conceptualization of resilience as a “successful adaptation and adjustment after experiencing an adverse, hostile, or negative event” (Holaday & McPhearson, 1997, p. 347) differs from the experience of burn injured individuals. For burn patients, resiliency is described as more of a process than an outcome measure—a continuous effort to move on with life as a person with a burn injury. The struggle to overcome a burn injury often co-occurs with emotional, physical, and social challenges that were nonexistent prior to the injury (Holaday & McPhearson). In children, postburn experiences vary as much as the characteristics of burn injuries. Whereas some children experience significant psychopathology, more than half of children were found to fare better and were thus able to avoid mental health concerns (Holaday & Terrell, 1994). One study reported that resilient pediatric burn patients had higher self-esteem, demonstrated better interpersonal skills, viewed others as more cooperative, and were more tolerant and coped more efficiently with stress overall than did nonresilient children (Holaday & Terrell, 1994). Further, a
longitudinal study of coping, personality and adjustment in adolescent females 10-11 years after burn injury described this population as experiencing lower levels of depression and demonstrating fewer behavioral problems than a control group. In addition, the participants reported higher levels of emotional stability, agreeableness, and extraversion on a personality assessment (Liber, Faber, Treffers, & Van Loey, 2007). Despite burn severity, within a sample of pediatric burn survivors who experienced a burn with a total burn surface area (TBSA) of greater than 80%, Blakeney et al. (1993) reported positive self-regard and indications that they were no more troubled than a comparison group of noninjured children.

The purpose of this chapter is to examine the protective factors that assist children in recovering from various types of adversity in particular, from burn injury. First, an overview of resilience will be provided, in addition to effective resiliency-building components. The resiliency overview will be followed by resiliency as related to burn injuries in children. Next, posttraumatic stress symptoms will be discussed, and related to traumatic injury. Then, there will be a discussion regarding burn injury in children and its impact on QOL, the psychological symptoms inherent in the pediatric burn population, and prevention programs/interventions available. Finally, the chapter will be concluded with the examination of posttraumatic stress symptoms in the pediatric burn population.

**Resilience**

Resilience has been conceptualized as a one-dimensional concept in which personal characteristics are present in various degrees and combine to form an individual’s personal characteristic factor of resiliency (Weiss, 2008). However, there has been extensive research regarding a two-factor model of resiliency, in which personal characteristics (described above) are affected by external risk factors, which combine to influence the type and amount of resiliency present in an individual (Weiss, 2008).
Prince-Embury (2007)—author of a widely used resiliency assessment instrument that was used in the current study (for details, see the method section)—tested one-, two-, and three-factor models related to the conceptualization and assessment of resiliency. Prince-Embury concluded that a three-factor model most appropriately captured the domains that contribute to resiliency. As such, the Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2007) includes the three domains that encompass resiliency: sense of mastery, sense of relatedness, and emotional reactivity. The concepts that are involved in those domains are described in Table 1.

Resilience is a multidimensional concept; it is not yet clear whether the factors that comprise resiliency influence a child’s likelihood of experiencing a traumatic event, whether they are a by-product of the stressful event itself, or whether the child possessed the factors prior to the stressful event.

Methods of Stress Conceptualization and Measurement

Research has identified a variety of adverse events (stressors) that test a person’s resiliency. These stressors range in severity from relatively minor incidents to catastrophic occurrences. The life events method is a commonly used approach to conceptualizing stress: Self-report measures are used to obtain information from respondents about stressful experiences that they have encountered typically in the recent past (Luthar & Zigler, 1991). Participants identify whether they perceived the event as desirable or undesirable and explain the extent to which it has affected their lives. The life events method has been criticized for its inability to discern causality; many events could either be conceptualized as stressors or as manifestations of maladjustment, i.e., a failing grade at school (Luthar & Zigler, 1991). In an effort to remedy the issue of the inability to identify causality, research (Luthar & Zigler, 1991) turned toward the examination of two distinct types of life events: those in control of the individual—and thus more likely to be attributed to maladjustment—and those viewed as out of the individual’s control—without
reasonable attribution to maladjustment. This research found significant relations between stress and adjustment in children, even in events out of the child’s control (Gersten, Langner, Eisenberg, & Simcha-Fagan, 1977; Luthar & Zigler, 1991). Results indicated that correlations between life event scores and adjustment are valid, even when manifestations of maladjustment are held constant (Luthar & Zigler, 1991).

Table 1

Organization of the Resiliency Scales for Children and Adolescents.

<table>
<thead>
<tr>
<th>Domain and Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of Mastery</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>A set of positive attitudes about the world in general and about an individual’s life specifically, currently, and in the future</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>The sense that one can master one’s environment, which is based on an internal expectancy about the impact of one’s behavior in specific domains</td>
</tr>
<tr>
<td>Adaptability</td>
<td>The ability to be personally receptive to feedback, to learn from one’s own mistakes, and to ask others for assistance</td>
</tr>
<tr>
<td>Sense of Relatedness</td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>The ability to receive and accept what is given</td>
</tr>
<tr>
<td>Access to Support</td>
<td>Perceived access to support as based on an underlying trust in relatedness</td>
</tr>
<tr>
<td>Social Comfort</td>
<td>Temperamental differences in comfort with others</td>
</tr>
<tr>
<td>Tolerance of Differences</td>
<td>The ability to have one’s own thoughts and express them even though they may be different from the thoughts of others</td>
</tr>
<tr>
<td>Emotional Reactivity</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>A set of positive attitudes about the world in general and about an individual’s life specifically, currently, and in the future</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>The speed and intensity of a child’s negative emotional responses</td>
</tr>
<tr>
<td>Recovery</td>
<td>Self-regulation or the speed of recovery from an intense emotion</td>
</tr>
<tr>
<td>Impairment</td>
<td>Level of impairment of functioning because of emotional arousal</td>
</tr>
</tbody>
</table>

Another way to study stress in relation to resilience is to assess every day, relatively minor stressors; the **hassles/minor stresses approach**. By assessing hassles or any frustrating experience that acts as an irritant, researchers can measure life stress and consequently predict various adjustment outcomes resulting from everyday stress (Luthar & Zigler, 1991). Lazarus (1984) argued that this method is superior to the life events method, because it provides us with a clearer picture of a person’s resilient factors. Due to their frequency, the ease of manipulation, and the ability to predict adjustment and health, everyday stressors are more indicative of an individual’s stress response and coping ability (Lazarus, 1984). Using the small events method, researchers have found that relatively minor hassles may be more predictive of resiliency outcomes than major life event scores (DeLongis, Coyne, Dakof, Folkman, & Lazarus, 1982). However, results are to be interpreted with caution because of it is argued that a major source of error exists with regard to the relations found between minor stressful events and outcome, which is potentially confounded by a person’s psychological health. For instance, *thoughts about death* is an item on an instrument that measures psychological distress as well as a measure of adjustment outcome (Luthar & Zigler, 1991).

A third approach to the study of stress is a **specific life stress** approach, which is the method used in the current study. The specific life stress approach is appropriate for measuring the effects of major traumatic life events such as severe disasters, familial stress (i.e., divorce), and severe illness/injury (Luthar & Zigler, 1991). Whereas this method can predict adjustment following a specific stressor, a limitation is an often-absent control group, which means that researchers are unable to discern whether competence levels of “resilient children” are comparable to those of well-adjusted children within the general population (Luthar & Zigler, 1991). Demographic variables can significantly affect resiliency levels, a factor that was controlled in the present study. Another common difficulty in research that investigates a traumatic life event is the absence of a baseline prior to the incident. Control groups cannot always remedy this situation, because certain
demographic and/or personal factors may predispose certain cohorts to experiencing a stressful life event; that is, child abuse is more commonly experienced by children who have difficult temperaments, but can also be a stressor that results in maladjustment (Luthar & Zigler, 1991). Further, trauma-exposed children range in onset of distress. While some experience immediate symptoms, others maintain a state of homeostasis weeks, months, or years after the event prior to exhibiting any trauma-related hardship (Joshi & Lewin, 2004).

Theoretical Models of Resilience

Garmezy et al. (1984) described three models of resilience versus vulnerability which explain the contribution of personal characteristics and stress on adjustment. The compensatory model is a simple one in which stressors and personal attributes combine additively to predict competence. For instance, when attributes are held constant, competence co-varies negatively with stress level. Conversely, holding stress constant, competence co-varies positively with strength of adaptive attributes. The compensatory model suggests that individuals can be protected from stress by personal qualities of strength. The challenge model describes a curvilinear relationship between stress and adjustment. In this model, stressors are defined as potential competence enhancers, given that stress levels are not excessive. Lastly, the protective factors model describes an interactive relation between stress and personal attributes that accounts for an individual’s level of adjustment; that is, personal attributes either dampen or amplify the impact as stress as a variable. Personal attributes that are positive, protective factors act as immunity against stress. Conversely, personal vulnerabilities serve to pronounce the effects of stress. The authors reported that these models are not mutually exclusive; they can be combined to explain coping from two perspectives that consider an individual’s personal attributes and stressful circumstances on the one hand, and adaptation to stress on the other.
Rutter (1987) also noted the relation between compensatory and protective factors. For instance, risk mechanisms—factors that lead directly to disorder—are discernable from protective processes or vulnerability factors. An individual’s level of adjustment is affected by the interaction of protective processes and vulnerability factors with risk variables, rather than having direct effects on their own.

Resilience and Burn Injury

Recently, there has been a call for more research regarding resilience and its relation to burn injury in children (Liber et al., 2007). For example, only three articles describing the outcome of pediatric burn patients appeared as a result of performing a literature search using the terms burn injury and resilience in the PubMed database in 2010.

Although resilience has been somewhat widely studied in relation to everyday stress, much less attention has been paid to traumatic events; this is especially relevant with regard to burn injury and is nearly nonexistent in the research concerning children. In 1997, Holaday and McPhearson performed a literature review and were able to identify only one article that addressed resiliency in severe burn survivors (Holaday & Terrell, 1994). The authors of that study rated 40 children and adolescents with severe burns as resilient ($N = 28$) versus nonresilient ($N = 12$) and found group differences in personality based upon Rorschach responses. In an effort to add to the nearly nonexistent literature regarding resilience in burn survivors, Holaday and McPhearson interviewed 39 adults who had experienced severe burns. Participants were divided into groups by age: 21 were 18 years and younger ($M = 14.1$ years) and 18 were adults ($M = 36.8$ years).

The average number of years between interview and burn injury was 6.7 years in the under-18 group and 12 years in the adult group. The content of interview questions was related to the burn experience, the participant’s definition of resiliency, personality changes, long-term consequences, social relationships, advice to other burn survivors, and advice for helping professionals. Regarding resilience, some of the overarching terms used
in the respondent’s definitions were *life gift, spirit, determination, struggle, courage,* and *motivation* (Holaday & McPhearson, p. 348).

### Building Resilience

Holaday and McPhearson (1997) conceptualized resilient factors as fitting into three categories: social support, cognitive skills, and psychological resources. To foster and maintain resilience in a child, it is important to build emotional expression and regulation, teach social skills and relationship building, and enhance effective communication and problem-solving skills (Joshi & Lewin, 2004). Effective resiliency-building programs focus on the already-present protective factors related to these areas, rather than the risk factors that are difficult to overcome (Joshi & Lewin, 2004).

Social support encompasses cultural influences, community support, school support, personal support, and familial support. Cultural influences that are most relevant for burn survivors relate to culturally accepted and sanctioned standards of beauty, which is problematic regarding media that promotes negative stereotyping of burn victims’ appearance. Burn survivors who experience community support feel more confident when appearing in public and fare better overall when they feel accepted within their community. Communities that offer safe, cohesive neighborhoods offer a feeling of safety and enhance resilience in societal members (Joshi & Lewin, 2004). School support is a key factor in the resiliency of children and adolescents. Those who receive encouragement to perform well socially and scholastically and are exposed to caring school personnel who promote high self-esteem and are intolerant of prejudice demonstrate higher levels of resilience. Additionally, schools that are structured, organized, and promote a safe and respectful environment more effectively foster resilience in students than do schools that have less structured, unsafe environments (Joshi & Lewin, 2004). Personal support is related to having a long-term relationship with someone outside of the family who is a consistent source of encouragement and unconditional positive regard (Holaday & McPhearson,
Children who seek out positive people and are motivated to perform well for the future show higher levels of resilience, in general (Joshi & Lewin, 2004). Familial support is a critical component of resilience in children and adolescents. Burn injuries cause significant disruption to the family unit, bringing considerable stress to the parents (Blakeney et al., 1993). Divorce rates are significantly higher in parents of a child with a burn injury. Mothers of burned children are particularly affected by their child’s injury, experiencing depression, anxiety, guilt, rejection, and phobic symptoms (Rivlin & Faragher, 2007). Family variables significantly influence the long-term psychosocial adjustment of a child following a burn injury (Landolt, Grubenmann, & Meuli, 2002). Family support that involves daily parental visits to the hospital following the burn injury, engaging in and maintaining family rituals, and holding behavioral expectations that remain unchanged, are all indicated to enhance resiliency (Holaday & McPhearson). In general, when parents take an active interest in their lives and activities, are stable, encourage family communication, and maintain consistent home routines, children fare better in terms of resilience (Joshi & Lewin, 2004).

The authors defined cognitive skills as related to intelligence, coping style, personal control, and assignment of meaning. Having average intelligence is a pre-requisite for resilience, as competence in understanding and reciprocating information through verbal and nonverbal communication is essential (Werner, 1982). Effective coping is also an important component to resiliency, especially due to the painful and long-term treatment inherent in burn injury. Avoidance and/or management of feelings of blame and guilt are positive coping skills that boost resilience. Personal control relates to an ability to take responsibility for personal care of health and physical problems. Being apprised of treatment procedures and participating when appropriate can support a burn patient in taking control and decreasing feelings of fear and helplessness (Armstrong, Gay, & Levy, 1994). Assignment of meaning refers to a burn patient’s ability to glean a sense of purpose
and learn something valuable from their injury, to experience a shift of perception following the traumatic event (Holaday & McPhearson).

Holaday and McPhearson defined their final component of resilience, psychological resources, as personality characteristics and dispositional attributes that are protective against stress. Some of the resources associated with resilience include an external locus of control, empathy, flexibility in new situations, novelty seeking behavior, and a sense of humor. Other personal characteristics include a willingness to seek and accept support, ability to tolerate frustration, empathy, and effective communication skills.

Resilience Intervention

In the absence of specific interventions related to fostering resilience in burn injured children, there are general recommendations for children who have been exposed to a traumatic event. Joshi and Lewin (2004) offered developmentally specific intervention techniques, which are critical to implement during the appropriate stage in a child’s development. Relevant to the current study, the authors focused on urging trained professionals to assess the child’s PTSS immediately following the trauma, in an effort to closely monitor children for impairment that requires early intervention by mental health professionals. They also recommended approaching intervention utilizing a family systems method, providing assessment, psycho-education and treatment to the family unit as a whole (Joshi & Lewin, 2004). There is a correlation between parental coping in the face of trauma and subsequent parental psychopathology following a trauma; parental psychopathology is a predictive factor of child psychopathology. Although a common sense precaution, removing a child and other family members from the immediate threat of danger is imperative, particularly relevant to children who have experienced a burn injury as the result of caregiver abuse or neglect. Following removal, continual symptom monitoring can be provided by individuals who maintain regular contact with the child (i.e., teachers, family members) and who have been trained to identify symptoms of
concern (Berkowitz, 2003) as PTSS can worsen diagnostically and require more intensive intervention if it presents as PTSD.

**Posttraumatic Stress and Traumatic Injury**

Posttraumatic stress disorder (PTSD) encompasses the reactions that individuals have to a traumatic event. That event is described in the *Diagnostic and Statistical Manual, Fourth Edition* (DSM-IV) of the American Psychiatric Association (APA) as one that involves the following (Criterion A1):

- an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate. (APA, 1994)

In children, symptoms of disorganized or agitated behavior in response to the event must be present (Criterion A2). The symptoms of PTSD include persistent re-experiencing of the event (Criterion B); persistent avoidance of stimuli associated with the trauma, a numbing of responsiveness (Criterion C); and increased arousal (Criterion D). There must be a persistence of psychopathological symptoms beyond one month of the posttraumatic event for a diagnosis of PTSD to be made (Criterion E). The disturbance must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (Criterion F).

Under each symptom, criteria are described which vary by individual experience. With regard to persistent re-experiencing of the event, the individual may have recurrent and intrusive recollections of the event (Criterion B1); experience recurring and distressing dreams about the event (Criterion B2); experience dissociative states in which the person behaves as though he or she is re-experiencing the event (tare; Criterion B3); and have intense psychological distress (Criterion B4); or physiological reactivity (Criterion B5) when exposed to triggering events that mimic the traumatic event. With regard to persistent
avoidance of stimuli that are associated with the event, an individual may avoid thoughts, feelings, or conversations regarding the event (Criterion C1); avoid activities, situations, or people that remind the person of the event (Criterion C2); experience amnesia for portions of the event (Criterion C3); experience diminished responsiveness to the external world (Criterion C4); feel detached from others (Criterion C5); have a reduced ability to feel emotions (Criterion 6), or have a sense of a foreshortened future (Criterion C7).

Finally, the individual will experience symptoms of anxiety or increased arousal that was not present prior to the traumatic event. Those symptoms include the following: difficulty falling or staying asleep, which may be due to recurrent nightmares (Criterion D1); irritability or outbursts of anger (Criterion D2); difficulty concentrating or completing tasks (Criterion D3); hypervigilance (Criterion D4); and an exaggerated startle response (Criterion D5).

Symptoms of posttraumatic stress experienced by children differ from those experienced by adults. Children are more likely to experience dreams of the event, which may evolve into nightmares involving a threat to self or others. A child’s play may be affected by a traumatic event, specifically through repetitive play that results in the child reliving the event. For example, a child involved in a car accident may reenact car crashes with toy automobiles. Children may experience such physical symptoms as headaches and stomach ache (APA, 1994). With regard to a child’s biological, social, and educational development, significant concerns emerge as a result of PTSD (Pynoos et al., 1993).

For purposes of this study, PTSS will be assessed via self-report and symptom severity will be reported. Posttraumatic stress symptoms will be defined as a continuum of symptoms present in children with burn injuries that are intrusive, yet not significant enough in strength or number to qualify for a diagnosis of PTSD. Although present in PTSD, sub-threshold posttraumatic stress symptoms are not significantly severe to warrant a diagnosis. Posttraumatic stress symptoms are, however, associated with increased impairment in functioning as well as comorbid mental health and behavior concerns.
(Daviss et al., 2000; De Vries et al., 1999). The assessment performed in the study is not diagnostic in nature; therefore, participants were not screened, diagnosed, or treated for PTSD.

Research suggests that PTSS persist in 30% of pediatric patients at 6 months post hospital discharge (Saxe et al., 2001). The trajectory of PTSS varies; while most children experience a decline in symptoms postinjury, a small minority can develop chronic PTSS and another minority group can exhibit delayed onset PTSS (Le Brocque, Hendrikz, & Kenardy, 2009). PTSS trajectory patterns in children are influenced by a number of risk factors. A longitudinal study by Le Brocque, Hendrikz and Kenardy (2009) investigated the course of PTSS in 190 children (ages 6-16) who had been admitted to general or intensive care pediatric units following a traumatic injury (Group 1: fractures, dislocations, and other injuries; Group 2: internal injuries, burn injuries, and multiple injuries). Data were gathered at six days after injury and follow-up data were collected at four to seven weeks and up to six months after injury. Variables of concern were child age, gender, type of injury and pretrauma behavior in relation to symptom trajectory patterns. Their findings suggest that three trajectory groups exist: resilient (57%; low symptoms following the trauma), elevated PTSS with quick recovery (33%; initially high level of symptoms with rapid recovery), and chronic (10%; high levels of acute and on-going symptoms; Le Brocque et al., 2009). Children who experienced chronic or elevated PTSS were more likely to have serious injuries (i.e., burns, internal injuries or multiple injuries) and pre-injury behavior concerns (internalizing and externalizing behaviors). Age was correlated with symptom trajectory, with younger age predicting high levels of acute symptoms with quick recovery phase.

There are known factors that increase the likelihood of a pediatric patient experiencing PTSS resulting in a traumatic injury (Bonner et al., 2008). Kahana, Feeny, Youngstrom, and Drotar (2006) performed a meta-analysis of the predictors of PTSS in children who had experienced a traumatic injury. The authors included 18 studies and noted the following results: socioeconomic status and social impairment were small to
moderate correlates of PTSD, while depressive and anxious symptoms, acute stress disorder, dissociation and appraisal of trauma severity and life threat displayed large effect sizes with PTSD severity (Kahana et al., 2006). Other research has found a correlation between PTSD and aspects relevant to medical intervention and hospital stay, including: unmanaged pain (Stoddard et al., 2009), acute dissociative symptoms during hospital stay (regarding burn patients; Saxe et al.), acute admission to the pediatric intensive care unit, high number of invasive procedures (Bonner et al., 2008), number of previous hospitalizations (Jones et al., 1992), and duration of hospitalization (Jones et al.). Child factors that heighten the likelihood of development of PTSD include female gender, younger age at the time of injury, preexisting psychopathology, prior sexual abuse (Daviss et al., 2000), and psychological vulnerability (i.e., previous exposure to stressful events; Bronner et al., 2008). Family variables, such as parental stress reactions and coping style, can also influence a child’s development of PTSD (Daviss et al., 2000; Saxe et al.).

In addition to the trauma of experiencing a significant injury, admittance to a pediatric intensive care unit (PICU) causes further stress that contributes to PTSS (Ward-Begnoche, 2007). Patients in the PICU endure painful, scary procedures (e.g., intubation, catheterization, wound debridement) which are not easily understood by nor explained to young patients (Ward-Begnoche). In addition to treatment stress, patients are under environmental stress when they are exposed to other patient’s procedure and/or deaths, alarms that indicate a code, and staff rushing to a patient’s distress (Ward-Begnoche).

Additional research is needed to discern other plausible factors (e.g., memory of the injurious event, invasiveness of medical procedures, and uncertainty of outcome) that increase the risk of PTSS for pediatric patients who have experienced a traumatic injury (Ward-Begnoche, 2007). Although not a goal of the current study, identification of the differences between injury- and treatment-related traumas is needed and will serve to help modify the medical care of pediatric trauma patients as well as help in the
development of psychological prevention and intervention of PTSS following a traumatic injury (Ward-Begnoche).

Burn Injuries in Children

Pediatric burns typically occur in children below age five (Drago, 2005; Dissanaike & Rahimi, 2009; Istre, McCoy, Carlin, & McClain, 2002), potentially associated with the impulsive, highly active, curious nature of this age cohort (Dissanaike, Boshart, Coleman, Wishnew, & Hester, 2009; Drago, 2005; Peck & Priolo-Kapel, 2002). One-year-olds are at the highest risk for scald injury, likely due to their proficiency in motor ability (i.e., grasping capability) combined with their undeveloped cognitive reasoning skills that do not allow them to perceive danger (Drago, 2005). Regarding gender differences, boys account for a larger proportion of pediatric burn injuries, with statistics ranging from over 50-70% of cases (Allen & Kagan, 2004; Drago, 2005). The higher incidence of burns for young males seems intuitively accurate, given their affinity for exploratory behavior (Drago, 2005) over their female counterparts and the higher incidence of misbehavior-related injuries in boys (Morrongiello, Ondejko, & Littlejohn, 2004). In their investigation of toddler injuries, Morrongiello et al. found that child factors related to sensation seeking, risk-taking, and ease of behavior management were most relevant to injury etiology. They did not find a correlation between child temperament and injury risk.

A study by Ghanizadeh (2008) found that burn injuries occur at a higher rate for children with attention deficit hyperactivity disorder (ADHD), which occurs at a higher rate in boys. In comparison of children with ADHD versus healthy controls, while two of the participants in the control group endorsed sustaining an accidental burn injury in the past, 13 of the ADHD group reported burn injuries resulting from inattention/impulsivity (n = 8), accidental causes (n = 2) and unknown causes (n = 3). In addition, 40.7% of the ADHD group had comorbid oppositional defiant disorder (ODD). Those with comorbid ODD experienced a higher rate of burn injury (16%) versus the participants with a single
diagnosis of ADHD (6.8%; Ghanizadeh). Parental factors that correlated with (not burn
specific) child injury included parents’ beliefs regarding their control over their child’s
health, beliefs about child supervision, and protectiveness (Morrongiello, Ondejko, &
Littlejohn, 2004). A study by Rimmer et al. (2008) found that 85% of the mothers in their
focus group sample of primarily Hispanic families were in the room with their child when
the burn injury occurred. This statistic emphasizes the rapid nature of burn injury
acquisition in combination with parents’ misbelief that parental presence is sufficient to
prevent child injury (Rimmer et al.).

There are demographic variables—unrelated to child factors—that are correlated
with burn injuries. Socioeconomic status is negatively correlated with accidents involving
fire: Lower income households experience a higher rate of fire-related deaths (Istre et al.,
2002). In a study that investigated residential fires in Texas, fire play accounted for 42%
of all injuries, 62% of deaths in children 0-4 years, and 94% of deaths in children who
live in apartments and mobile homes. Most of the injuries related to fire play resulted
from children playing with matches or lighters and fires started in a bedroom (Istre et al.).
Smoke alarms were found to offer no protection against injury or death resulting from
fire play or arson (most of which occurred in apartments and mobile homes), but did
provide significant protection related to fires started from other causes. The authors
hypothesized that this finding could be due to the placement of the fire alarm or due to
the nature of the child’s behavior in play-related fires (Istre et al.).

The leading cause of burn injury in children, scald burns are associated with a
greater chance that hospitalization and intravenous fluid resuscitation are needed (Lowell,
Quinlan, & Gottlieb, 2008; Lyngdorf, 1986; Rimmer et al., 2008). Each year in the U.S.,
100,000 children sustain scald injuries from spilled food and beverages (Palmieri et al.,
2008). Scalds are also commonly acquired through tugging on tablecloths, pulling the
electrical cords of appliances that dangle from kitchen counters, transporting hot liquids,
climbing to reach something that is hot, and opening a microwave oven to retrieve a hot
substance (Allen & Kagan, 2004; Dissanaike et al., 2009; Drago, 2005; Lowell et al.). In the U.S., hot noodle soups (which have a long cooling curve) are the most common cause of unintentional scalds (Palmieri et al., 2008). A significant portion of scald injuries occur when toddlers are supervised by children 7-14 years old who handle such food items as hot noodle soups and hotdogs that are prepared in the microwave and then removed when the toddler is in the vicinity (Lowell et al.).

Dissanaike et al. (2009) investigated burn injuries in 541 pediatric burn patients and found cooking-related injuries to be the leading cause of burns, primarily in toddlers (average age of 2.7 years). Common hot substances responsible for the burn injury included: soup (27%), grease (26%), coffee (18%) and beans (9%). Nearly 50% of the burns occurred when a child pulled the substance down from a height; this typically causes a burn primarily to the chest and shoulder region. The outcome of a typical cooking-related injury in this study was an average TBSA burn of 7%, with a hospital stay of approximately four days and a low mortality rate of 1% (Dissanaike et al., 2009).

A study by Allen and Kagan (2004) was conducted with 196 pediatric burn victims to identify the relation between burn injury severity, hospital resource consumption, and child outcome in children who sustained a burn after pulling a container of grease or hot liquid onto them. In the sample, 54 (27.6%) burn injuries were caused by grease or oil, while 142 (72.6%) were caused by other liquids (Allen & Kagan). Demographic results indicated that the average age of children burned was three years old and that slightly more than half were males. With regard to burn injury characteristics, the average TBSA was 18.3% for children burned by grease and 14.4% for children burned by a different liquid. Grease burns resulted in an increase in the need for more aggressive medical care, with 56% requiring skin grafting (34% of the nongrease group), 20% on ventilation (6.3% of the nongrease group), and 22.2% requiring a stay in the PICU for an average of 16.8 days (6.3% of the nongrease group for an average of 9.1 days; Allen & Kagan). This study
revealed the danger of grease fryers and the need for an increase in safety of product design and product labeling/instruction to decrease pediatric grease burns (Allen & Kagan).

Although scalds are the most common type of pediatric burn, flame burns (such as those caused by house fires) can be most devastating: They cause inhalation injuries which have a higher association with morbidity and mortality (Palmieri et al., 2009). Young children and the elderly are at the highest risk for fatality caused by house fire injury (DiGuiseppi, Edwards, Godward, Roberts, & Wade, 2000; Warda, Tenenbein, & Moffatt, 1999). Due to their inability or unwillingness to leave a burning room, children are more frequently affected by inhalation injury; outcome for a child with inhalation injury is influenced by the TBSA and thickness of the burn; children typically spend one day in the hospital per percent of TBSA (Palmieri et al.).

Research has shown that additional risk factors regarding involvement in a house fire (causing fatal and nonfatal injury) include the following: male gender; racial minority status; low socioeconomic status (SES); disability; geographical residence in rural areas, central urban areas, and regions of the southern U.S.; and occurrence in the late night or early morning hours (Warda et al.). Factors that affect the probability of sustaining a fatal versus nonfatal injury include residing in a home that lacks safety features such as a smoke detector, telephone, or adequate number of exits (especially within mobile homes and substandard houses) and engaging in cigarette and/or alcohol use (Warda et al.).

Peck and Priolo-Kapel (2002) performed a meta-analysis of articles on child abuse by burning from 1966 to 2000 and discovered 134 articles on the subject. Approximately 6-20% of child abuse is caused by burning (Peck & Priolo-Kapel). Accurate statistics are difficult to estimate due to the difficulty in diagnosing child abuse by burning (especially in young children with limited verbal skills). Typical demographics of abused children include young age (children one to three years old are most at risk, perhaps due parental stress); African American (particularly within single-parent households); and adolescent parents. For preschoolers, abuse is more likely during toilet training, especially when
toileting accidents occur. The parent-child relationship is a factor that affects abuse: Impaired parent-child bonding due to mental retardation, congenital abnormalities, and prematurity is related to higher incidences of abuse, along with poor parent-child interactions (i.e., role reversals). Children who are abused characteristically demonstrate inappropriate behavior such as clinginess, excessive or absent crying, apathy, and lethargy. Children under 18 months may demonstrate inconsolable crying. Child records may show previous investigation by child protective services, a poor immunization record, and health mismanagement (Peck & Priolo-Kapel).

Peck and Priolo-Kapel (2002) also identified characteristics of abusive parents. As previously mentioned, single-parent families are at greater risk, especially those with low SES. Stressors such as substance abuse, unemployment, mental illness, and substandard housing were linked to greater rates of child abuse. Parents lacking external support systems, in addition to being isolated, demonstrated a greater risk for child abuse. The authors found that many abusers had themselves been abused or neglected as children; abusers were found to engage in violent interactions within the parental relationship and to demonstrate poor impulse control. Their expectations for their child are inconsistent with typical child development, and they rely on their children for emotional support, i.e., role reversal (Peck & Priolo-Kapel).

Quality of Life Following a Burn Injury

When a pediatric patient’s ultimate outcome with regard to adjustment following a burn injury is considering, QOL is arguably a crucial component of the assessment process. The current study included a measure aimed at gathering QOL data, because social validity largely rests upon a child’s day-to-day functioning across multiple domains. In conceptualizing QOL, because several factors contribute to the designation, there is disagreement on a universal definition (Pope, Solomons, Done, Cohn, & Possamai, 2007). Research has indicated that pediatric burn patients typically have good QOL outcomes
(Herndon et al., 1986; Landolt et al., 2002; Pope et al., 2007; Sheridan et al., 2000). With regard to children and adolescents, researchers have proposed the following factors be considered in the definition of quality of life: developmental history and child mental status examination (Herndon et al., 1986); pain and symptoms, motor functioning, independence, cognitive and emotional functioning (Landolt et al., 2002); social skills (Blakeney et al., 1998, Landolt et al., 2002); academic performance, behavioral concerns, and parental stress (Blakeney et al., 1998); and independence in performing daily living activities (Myers-Paal, Blakeney, Robert, Murphy, & Chinkes, 2000; Herndon et al., 1986). Although many of the aforementioned studies indicated that children were able to maintain a positive QOL following a traumatic injury, the results were mainly based on parent ratings and research observation, rather than on child report (Pope et al., 2007). In fact, Landolt et al. (2002) found that parents of a burn-injured child endorsed witnessing less positive emotions in their children than did parents of a noninjured child. A study by Pope et al., which included pediatric burn survivor and control samples, indicated that children and adolescents who had sustained burn injuries reported higher QOL, more positive weight satisfaction, and more positive beliefs of how others view their appearance than a healthy control group. However, as the reported TBSA increased, the QOL rating decreased (Pope et al.).

Additional conflicting studies have investigated the effect of TBSA on QOL. Regarding children with massive burn injuries (i.e., involving more than 70% TBSA), limited data indicate that QOL is typically favorable. Herndon et al. (1986) conducted a four-year follow-up study of 12 children who had survived massive burn injuries (defined by greater than or equal to 80% TBSA, 70% third-degree burns) and reported that QOL (though not globally defined) was acceptable. Specifically, these individuals retained age-appropriate functional performance (i.e., feeding self, walking independently), performed at an average academic level, and endorsed extracurricular activity participation. However, the authors also cautioned that the final outcome for children who sustained major burn injuries could not be
accurately assessed until they enter late adolescence and early adulthood, when intimate relationships with the opposite sex in addition to physical and emotional development (which becomes more definitive following further surgical procedures) become more relevant (Herndon et al., 1986).

Only one other study regarding QOL outcome related to significant burn injuries has been performed since the Herndon et al. (1986) study. Sheridan et al. (2000) evaluated 80 patients who were younger than 18 years ($M = 8.8$ years) at the time that they sustained their massive burn injury. The authors used Short Form 36 (SF-36; McHorney, Ware, & Raczek, 1993), a health-related QOL measure which assesses domains of general health, physical functioning, social functioning, physical role, emotional role, mental health, energy/vitality, and bodily pain. Sheridan et al. also gathered demographic information, burn injury-related data, and information regarding activities postdischarge. Their results indicated that overall their participants reported satisfactory QOL that was comparable to the age-matched general population. Factors that favorably influenced the positive outcome were the following: having a supportive, intact family; early reintegration with pre-burn activities and consistent follow-up (i.e., four times annually for two years following the injury) in a burn treatment clinic. Although the results in general indicated favorable QOL outcomes, 15% and 20% of patients had scores two standard deviations below the average range with regard to physical functioning and physical role, respectively. These findings indicate lingering, severe physical disability in this portion of the sample population (Sheridan et al., 2000).

Research suggests that family and demographic characteristics contribute to QOL; counterintuitively, burn injury characteristics (e.g., TBSA, location of burn) are not important predictors of long-term adjustment (Landolt et al., 2002; Sheridan et al., 2000). Studies have found that supportive family relationships contribute to a positive outcome—defined by greater family cohesion, higher expressiveness, and less conflict within the family (Blakeney et al., 1988; Landolt et al., 2002; Sheridan et al., 2000). Additional
factors that positively influence QOL following a burn injury include appropriate access to special education resources, successful reconstructive surgeries, participation in physical and occupational therapy, psychological therapy for the burn survivors and their parents, engagement in activities that evoke positive sense of self (Herndon et al., 1986) and younger age at time of burn (Landolt et al., 2002).

For pediatric burn survivors who qualify for a diagnosis of PTSD, their QOL is significantly more impaired than for those who do not develop PTSD following a burn injury. Within this population, social functioning is significantly impaired, whereas all other aspects of health related QOL (i.e., physical, cognitive, and emotional dimensions) are highly correlated with PTSD severity (Landolt et al., 2009). Children with PTSD experience decreases in physical (e.g., bodily complaints) and emotional functioning (e.g., feelings of sadness; Landolt et al., 2009).

The current study included parent and child/adolescent QOL questionnaires (PedsQL 4.0, Varni, Seid, & Kurtin, 2001) to further investigate the relation between demographic and burn injury characteristics and QOL outcome in relation to PTSS.

**Burn Injury Prevention**

The results of the current study are intended to inform prevention programs by identifying children who are in need of burn education (participant characteristics related to burn injury incidence) and to strengthen interventions by identifying resilience factors associated with healthy adjustment. Research indicates a need for updated burn injury prevention programs, because experts have deemed most childhood burns as preventable (Rimmer et al., 2008). Alarming results of a focus group that primarily consisted of Hispanic parents residing in the Arizona area revealed that 85% of its members had not come into contact with any type of burn prevention education (Rimmer et al., 2008). This highlights a need for widespread education.
A current burn injury prevention method focuses on setting hot water heater temperatures to less than 120 degrees Fahrenheit (Rimmer et al., 2008); however, 90% of child scalds involve liquids other than tap water (Lowell et al., 2008). The efficacy of Injury Prevention Program Sheets is questionable, because they do not offer effective means for preventing acts that result in the most common burn injuries—i.e., keeping pot handles turned toward the back of the stove, keeping hot substances out of a child’s reach, and not carrying a child while holding a hot substance (Lowell, et al.). The promotion of flame-retardant sleepwear has helped to reduce the risk of burn injury for children in the home (Schieber, Gilchrist, & Sleet, 2000). Smoke detector programs that promote use and maintenance are crucial in neighborhoods of low-income housing. However, the most effective program in reducing house fire injury should involve implementing housing improvements, enacting disposal of hazardous materials, and promote smoking cessation and lessen alcohol use (Warda et al., 1999). Warda et al. urged the combining of fire department and public health resources to promote burn injury surveillance and preventive program evaluation.

Turner, Spinks, McClure, and Nixon (2007) performed a meta-analysis of the literature related to community-based prevention programs for burns and scald injuries. Of the 39 studies that were identified, only two included prevention programs that resulted in significantly positive results. Those studies described multi-strategy, community-based intervention programs (Peleg, Goldman, & Sikron, 2005; Ytterstad & Soggard, 1995). The study by Peleg et al. involved an investigation of hospitalization for burn-related injuries in Israeli communities where in a burn prevention program had been implemented versus communities that had no such program. Peleg and colleagues found that the interventions that consisted of one-on-one guidance sessions, group training sessions, and distribution of reading materials and safety accessories were effective in decreasing hospitalizations due to burn injury by 25%. The second study (Ytterstad & Soggard) involved an investigation of burns in children below age five in a Norwegian city. The Harstad Injury Prevention Study
is modeled after the Manifesto for Safe Communities from the World Health Organization (WHO, 1999, as cited in Turner et al., 2009) and promotes building community enthusiasm toward enhancing safety and reducing injury. The effort involves education of burn injury prevention and information on first aid treatment. The message is encouraged at one-on-one counseling sessions by public health nurses and promoted by advertisement at fairs, shopping malls, and local media. Specifically, the program promotes a reduction in hot water temperature and cooking safety tips (Ytterstad & Soggard). Results from the intervention indicated that in 1998 the incidence of burns and scalds had decreased by 57.5%; this was compared to a baseline measure taken before the enactment of the prevention program.

Unfortunately, the labor-intensive nature of these programs restricts large-scale use for communities that lack resources and research abilities (Turner et al., 2007). Rimmer and colleagues (2008) suggested implementing small group classes that promote safety and prevention to communities. Palmieri et al. (2008) described a larger scale soup scald prevention plan that would involve a revision of the packaging of convenience soups. In fact, the authors created a specific soup container mock-up that could serve to prevent burn injuries. They also encouraged outreach campaigns at schools and fairs to promote patient education. Promoting first aid treatment tips is a crucial component of education, because misguided home remedies (i.e., using a substance other than cool water to initially treat a burn) could potentially worsen the burn and lead to a greater chance of infection (Rimmer et al., 2008). Severity of pain associated with the burn injury has been shown to be associated with PTSS in children and adolescents with burn injuries (Stoddard et al., 2009).

Posttraumatic Stress in Burned Children

Similar to resilience and pediatric burn injury, little research has addressed posttraumatic stress in pediatric burn patients (Pardo, Garcia, Marrero, & Cia, 2008), despite the notable prevalence of such symptoms within the population. Studies estimate
approximately 30% of children and adolescents with burn injuries experience symptoms of posttraumatic stress within the six months that follow their burn injury (Saxe et al., 2005). Despite the significance and relevance of PTSS in pediatric burn patients, more research has been devoted to investigating other psychopathology (some related to PTSS) in pediatric burn injury survivors.

Stoddard, Saxe, et al. (2006) investigated acute stress symptoms in young children with burn injuries and found that 29% of 52 children endorsed acute stress symptoms. With regard to acute stress disorder, 80% met the criterion for re-experiencing, 62% for avoidance, and 39% for arousal. The authors conducted a path analysis to identify risk factors related to acute stress and found that pain, pulse rate, size of burn, and parents’ acute stress symptoms contributed to the development of acute stress symptoms (Stoddard, Saxe, et al., 2006). Noronha and Faust (2007) investigated the strength of association between impact variables (i.e., burn injury and demographic characteristics) and psychological adjustment following a burn and found that body location of the burn injury had the most impact on a pediatric burn patient’s adjustment. The authors purported that these findings could be associated with the pain and functional loss that are associated with the location of the burn injury on the body.

Davydow, Katon, and Zatzick (2009) performed a meta-analysis of studies that investigate psychiatric outcomes for individuals who have experienced burn injury, trauma, or intensive care unit (ICU) stays and reported risk factors for PTSD within that population. Davydow et al. identified the following potentially problematic characteristics: experiencing increased acute stress immediately following the injury, a stay in the ICU following the trauma, prior traumatic history, female gender, stimulant intoxication/benzodiazepine use preceding the trauma, elevated heart rate upon arrival to the hospital, and experience of a subjective life threat due to the trauma. Stoddard et al. (2009) reported a significant correlation between the morphine dosages given to one- to four-year-old burn
patients in relation to a decrease in PTSS; this finding suggests that the amount of pain experienced is positively correlated with PTSS severity.

Saxe et al. (2005) reported that the child’s age, size of a child’s burn, and the level of pain contributed to an increased level of acute separation anxiety. Separation anxiety is especially relevant to pediatric burn patients due to the nature of the prolonged hospital stay and frequent separations from the parent during treatment; this occurs when comfort and parental support is especially needed (Saxe et al., 2005). Further, children who experienced the most anxiety during separation from a parent were most likely to develop PTSS. Saxe et al. (2005) also found that the size of the child’s burn was associated with an acute dissociative response—a response that was a direct predictor of PTSD symptoms. Another study found that TBSA and number of days since hospital discharge were associated with social and behavioral difficulties in pediatric burn patients (Davydow et al.).

Children who have sustained burn injuries are at a greater risk than their healthy counterparts for psychopathology including phobias, anxiety, and enuresis (Stoddard et al., 1989). In the short- and long-term aftermath of a burn injury, children and adolescents have also demonstrated an increase in incidence of attention and behavioral disorders (Pardo et al., 2008). Stoddard, Stroud, and Murphy (1992) reported that approximately 13% of pediatric burn patients experienced depressive symptoms after burn injury. Relevant to those findings, children who have sustained a burn injury have demonstrated a decrease in positive emotions and may experience social withdrawal and somatic complaints (Davydow et al.).

Given the paucity of research regarding PTSS in pediatric patients with burn injuries, the importance of the current study is emphasized. Combined with the virtually nonexistent research regarding resilience in pediatric burn patients, an analysis of resilience and PTSS in pediatric burn patients is warranted. The absence of simultaneous study of resiliency and PTSS related to pediatric burn injury calls for an investigation of a relation
between those factors, which are potentially crucial elements for proper prevention,
assessment, and intervention of PTSS in pediatric burn patients. Research is needed to
understand the risk factors for PTSS in burned children and to understand which protective
factors aid in preventing the occurrence of such symptoms (Ward-Begnoche, 2007).
CHAPTER III
METHODOLOGY

The following chapter is divided into three sections. In the first section, participant characteristics and inclusionary factors will be described. This will be followed by a discussion of the data collection procedures and description of intake/demographics and informed consent/assent forms. Next, psychometric properties of the assessment instruments will be described. The Resiliency Scales for Children and Adolescents (RSCA; Prince-Embrey, 2007) was used to assess resiliency; the UCLA PTSD Reaction Index for DSM-IV (Reaction Index; Pynoos, Rodriguez, Steinberg, Stuber, & Frederick, 1998) was used to assess posttraumatic stress symptoms; and the Pediatric Quality of Life Inventory, Version 4.0 (PedsQL 4.0, Varni, Seid, & Kurtin, 2001), was used to gather health-related QOL information. Finally, the data analysis will be explained.

Participants

There were two requirements for study participation; the individual must have sustained a burn injury severe enough to require medical care within a local university hospital, and must have been between the ages of 9-18 at the time of data collection. The university burn treatment center is the only burn center in its state and has been verified as an adult and pediatric burn center by the American College of Surgeons/American Burn Association since 1996. The burn service includes 16 beds within the burn treatment center and burn clinic. Participants were identified for recruitment via a burn camp registry, which contained names and addresses of pediatric burn patients who were eligible for attending the burn camp. The first data collection attempt was from children and adolescents attending a burn camp that was sponsored and run by the local university hospital. The burn camp was established in 1995 and is a weeklong event offered at no cost to children ages 8-18 who have sustained a burn injury, other traumatic injury, or wound requiring skin grafting. The camp is conducted by staff consisting of professional firefighters, burn
survivors, burn care professionals, and YMCA camp experts. All campers were eligible for participation, with the exception of eight year olds. From this pool of 40 campers, 10 participated. Common reasons for nonparticipation cited by parents and caregivers included the extensiveness of the time commitment required for questionnaire completion and unwillingness to expose a child to a situation that may elicit emotional distress. Children refused participation because they did not want to delay participation in camp festivities or simply told their parent/caregiver “no” without further explanation when they were asked if they wanted to participate.

Due to insufficient participant recruitment during the initial data collection attempt, a second recruitment was initiated via mail. Participants were drawn from the same burn camp registry of pediatric burn patients used for the first round of data collection. The registry contained names of patients who had attended the burn camp; therefore, the names and contact information for patients who participated during the first data collection were removed. The mailer was sent approximately six months following the completion of the burn camp, subsequent to modification approval by the IRB. The mailer was sent to 153 patients (including those who chose not to participate previously at the burn camp), and three were returned to sender due to addressing issues. From a pool of 150 potential participants, 10 participants returned completed packets. Therefore, the final sample consisted of 20 participants—a participation rate of 8%. There were 13 male and 7 female participants. The age of participants ranged from 9 years, 8 months to 18 years, 7 months. Due to lack of variability of income, household income was categorized into annual incomes of less than $50,000 ($n=10) and annual incomes of more than $50,000 ($n=10). The demographics of the location of data collection reflect a substantially homogenous population of Caucasian ethnicity; therefore, ethnicity information was not gathered to protect the confidentiality of the participants.
Procedure

Human Subjects approval was obtained before starting the study from the University of Iowa Institutional Review Board (IRB). A mailer was sent several weeks before the start of burn camp to 40 camp attendees and contained an explanation of the study, an intake/demographics form, and informed consent form. (See appendices A-C). If they were willing to participate, the parents or legal guardians of the attendees were able to review the study prior to the evening of camp check-in and to complete the informed consent and intake forms. The parents/legal guardians were asked to return the forms when their child checked in for camp. The camp attendees checked in at the university hospital and participated in an overnight stay that was held at the hospital the night preceding the start of the burn camp. From there, attendees boarded a bus and traveled several hours to the burn camp area. The check-in provided an opportunity to perform data collection in a controlled and organized environment; this ensured that each camper was approached regarding the study and was provided an opportunity to ask questions while the consent/assent forms, demographics/intake form, and questionnaires were completed. The parents/legal guardians who were present at check-in had the option to ask questions about the study and to complete the consent/intake forms during that time if they so chose. Participants who were 13-17 years old read and signed the informed consent form with their parent/legal guardian. Following informed consent, participants who were 9-12 years old were provided an explanation of the study and signed an assent form (Appendix D). The parent/legal guardian completed the intake/demographics form (if they had not previously done so) and a parent questionnaire while the child completed three questionnaires. Participants who were 18 years old completed the same forms as the adolescent participants; parent consent forms were not required for this population. Parents of 18-year-old participants were also asked to complete the parent questionnaire.

Participants recruited via mail received the same forms as previously described, with the exception of the informed consent/assent forms. These forms were not required,
because return of the forms implied consent. They were provided with a cover letter and
information summary (Appendix E) that explained the purpose of the project and requested
their participation. The summary included information on how confidentiality was
maintained and information about how to contact the researcher was provided. Participants
were asked to return the intake form and questionnaires within three weeks of receipt, using
a self-addressed stamped envelope that was included in the packet. Participants were
notified that they would not be contacted following participation in the study. Participants
were notified that they would be entered into a drawing for one of two $25 gift cards to a
nationally known retail store upon receipt of their completed materials. Burn camp
participants were also eligible for this drawing.

Completed questionnaires were collected upon return and data was entered into the
computer for analysis. To ensure confidentiality, participants were assigned a code and
personal information was kept separate from the data. Participant names were retained for
access to medical records, and addresses were retained for identification for gift card
reimbursement purposes. Once data analyses were completed, participant information was
destroyed to ensure confidentiality.

**Intake/Assessment**

**Informed Consent/Assent**

The informed consent followed the standard wording as required and approved by
the IRB. The form explained the study and provided research team contact information for
participants with further questions. For the purposes of the current study, access to the
child’s medical records was requested. Although not a requirement for participation,
accessing medical records related to the burn injury was helpful for gathering information
related to the date the burn occurred, the percentage of total body surface area injured (%
TBSA), location of the burn injury, number of surgeries related to the injury, number of
days spent in the hospital following the injury, whether other individuals were injured as a
result of the incident and their relationship to the participant, and a description of how the
burn injury occurred. In lieu of providing consent for access to participant medical records,
the parent/legal guardian had the option of providing the information on the intake form.
For purposes of ease of participation and data collection accuracy, access to participant
medical records was preferred. Once the informed consent process was complete, the
participant was given an assent form to review and sign, along with an age-appropriate
description of the study and the child’s requirements. Once the assent process was
complete, the parent/legal guardian was provided an intake/demographics form to complete
(if not previously completed), while the participant completed three questionnaires.

Intake Form

The intake form consisted of demographics variables, including the child’s date of
birth, gender, household income, and psychological diagnoses of the child. In addition, the
burn injury information mentioned above (i.e., the date the burn occurred, % TBSA,
location of burn injury, etc.) was included on the form as optional for parents/legal
guardians who chose not to grant access to medical records or for those who chose to
complete the section in addition to granting access. Completion of the intake form required
approximately five minutes or less.

Resiliency Scales for Children and Adolescents

As the parent/legal guardian completed the intake form, the participant completed
the Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2007; see
Appendix F), a measure consisting of three self-report scales that assess the child’s sense of
mastery (20 items within subscales of optimism, self-efficacy, and adaptability), sense of
relatedness (24 items within subscales of trust, support, comfort, and tolerance), and
emotional reactivity (20 items within subscales of sensitivity, recovery and impairment).
The participant responds to items on a five-point Likert scale regarding frequency: 0 =
never, 1 = rarely, 2 = sometimes, 3 = often, and 4 = almost always. Regarding the Sense of
Mastery scale, a higher score indicates a higher sense of mastery and more resilience. Likewise, a higher score on the Sense of Relatedness scale indicates an increased sense of relatedness and more resilience. Conversely, a low score on the Emotional Reactivity scale indicates less emotional reactivity and more resilience.

The scale is written at a third-grade reading level and is appropriate for individuals ages 9 to 18. Prince-Embury and Courville (2008) investigated the factor structure of the RSCA and found that it did not vary across gender and age, indicating that the instrument is appropriate for use with males and females between the ages of 9 and 18.

A study by Prince-Embury (2009) investigated the association between parent education level and scores from the RSCA, and found a significant main effect of emotional reactivity for children with parents at the highest and lowest levels of education. Children of parents with low levels of education ranked highest on the scale, whereas children of parents with a high level of education ranked lowest on the scale. Also, on the Sense of Relatedness scale, children of parents with less than a high school education reported significantly less sense of relatedness than children from any of the three groups whose parents had higher levels of education. Although parent education level was not a variable studied in the current study, household income is positively correlated with education level (Prince-Embury, 2009).

Another study by Prince-Embury (2008) found significant correlations between the Beck Youth Inventory–II (BYI-II) and all the RSCA scales and indices. Particularly, positive associations (and the strongest correlations) were found between the BYI-II scores and the RSCA Vulnerability Index and Emotional Reactivity scale scores. These results indicate that the RSCA is appropriate for use in preventative screening for psychological vulnerability. Of note, the author also found psychological vulnerability (emotional reactivity, specifically) to be strongly related to self-reported symptoms, more so than personal resources such as sense of mastery and sense of relatedness (Prince-Embury, 2008).
Alpha coefficients for the three scales across age (between ages 9 and 14) and gender groups have been reported as follows: Sense of Mastery Scale ranged from .85 to .89; Sense of Relatedness from .89 to .91; and Emotional Reactivity from .90 to .91 with test-retest reliability correlation coefficients for the three global scales from .79 to .95 (Prince-Embury, 2007). Internal consistency was excellent for the three scales for 15-18 year olds. Alpha coefficients and test-retest reliability were as follows: internal consistency for the Sense of Mastery scale was excellent at .95 with a test-retest reliability coefficient of .86. The alpha coefficient for the Sense of Relatedness scale was .95 with a test-retest reliability coefficient of .86. Internal consistency for the Emotional Reactivity scale was also excellent at .94 with a test-retest reliability coefficient of .88 (Prince-Embury, 2008).

Validity of the RSCA has been established through a confirmatory factor analysis, in which a three-factor model of resiliency represented the three scales and their subscales (Thorne & Kohut, 2007). In addition, results of several correlational studies show evidence of convergent and divergent validity. When compared to the Reynolds Bully Victimization Scale (BVS; Reynolds, 2003), moderate correlations between the two scales were evident when 47 children were tested. Those who experienced higher levels of bullying on the BVS had higher levels on the Emotional Reactivity scale and endorsed lower levels on the Sense of Mastery and Sense of Relatedness scales (Thorne & Kohut). With regard to criterion validity, the RSCA has demonstrated reasonable sensitivity in distinguishing individuals with psychological diagnoses (i.e., ADHD, bipolar, conduct disorder, anxiety and depression) from those without (Thorne & Kohut).

UCLA PTSD Index for DSM-IV

Following the completion of the RSCA (Prince-Embury, 2007), participants were given the UCLA PTSD Reaction Index for DSM-IV (Reaction Index; Pynoos et al., 1998; see Appendix G), a measure intended for use with traumatized children and adolescents. The Reaction Index (Pynoos et al., 1998) is a paper-and-pencil screening instrument for
assessment of trauma exposure and subsequent post traumatic stress symptoms and is available in child and adolescent versions. Both were modified slightly for the current study, as suggested by the authors of the instrument (Steinberg, Brymer, Decker, & Pynoos, 2004). In the directions given to the respondent, the authors have suggested that the specific traumatic event be inserted in place of “the bad thing that happened” into the phrase, “answer how you felt during or right after the bad thing that happened.” In the current study, the respondent was asked to “answer how you felt during or right after you were burned.” The original version of the Reaction Index (Pynoos et al., 1998) includes a section that is used to categorize the traumatic event. Since all participants were exposed to the same incident (a burn injury), that portion of the assessment was omitted. Therefore, the assessment began with Part II (13 yes/no items), created for evaluation purposes of the A1 and A2 criteria of the DSM-IV that cover objective and subjective features of the traumatic event. The difference between the child and adolescent version is in Part III; the adolescent version includes two additional items pertaining to irritability/anger and pessimism regarding the future. Part III (20 items in the child version; 22 items in the adolescent version) evaluates DSM-IV symptoms for criteria B (intrusion), C (avoidance), and D (arousal) for PTSD. The criteria are measured by the frequency of the occurrence of PTSS during the past month (0 = none of the time to 4 = most of the time). In addition to assessing the DSM-IV criteria, the authors added two items which measure fear of recurrence and trauma-related guilt, which they believe are clinically relevant topics regarding PTSD (Pynoos et al., 1998). Although the measure assesses DSM-IV diagnostic criteria and indicates whether the respondent meets partial or full diagnosis of PTSD, the purpose of the current study was not diagnostic. Therefore, rather than categorizing participants into groups with labels of PTSD versus no PTSD, PTSS was measured and conceptualized as a continuum of posttraumatic stress symptom severity in participants. The symptom severity data was summarized in a table, which indicated the average severity scores for DSM-IV PTSD criteria B, C, and D across participants.
The UCLA PTSD Reaction Index (Pynoos et al., 1998) has been translated and used in evaluation, research, and screening/recovery programs internationally (Steinberg et al., 2004). The measure has been used in situations of natural disaster, political violence, community violence, personal assault, witnessing of suicide, and traumatic injury and illness (Steinberg et al., 2004). Validity of the instrument has been demonstrated in numerous studies by the findings of higher Reaction Index scores in populations who have experienced a trauma versus the control group, along with an apparent dose of exposure relationship of Reaction Index scores across exposure groups (Steinberg et al., 2004). For example, Pynoos et al. (1993) investigated posttraumatic stress in children who were involved in the 1988 earthquake in Armenia and were able to correctly identify, using a cutoff score of 40, 78% of their participants as meeting DSM-III-R diagnosis of PTSD and 79% of those who did not. The DSM-IV version has good convergent validity at 0.70 (in comparison with the PTSD Module of the Schedule for Affective Disorders and Schizophrenia for School-Age Children, Epidemiologic version), with a cutoff score of 38 having a sensitivity of 0.93 and specificity of 0.87 in detecting PTSD (Rodriguez, Steinberg, Saltzman, & Pynoos, 2001; as cited in Steinberg et al., 2004). With regard to consistency, Roussos et al. (1999) reported a test-retest reliability of 0.84 when the index was used with children who had experienced a moderate earthquake. Further, the findings indicated that the PTSD score was the single most powerful predictor of depression.

Pediatric QOL Inventory, Version 4.0

In addition to the RSCA (Prince-Embury, 2007) and UCLA PTSD Reaction Index (Pynoos et al., 1998), participants completed the Pediatric QOL Inventory, Version 4.0 (PedsQL 4.0, Varni, Seid, & Kurtin, 2001; see Appendix H) a measure intended for use with either healthy or chronically ill or injured children and adolescents. The PedsQL 4.0 (Varni et al., 2001) is a paper-and-pencil screening instrument for assessment of health-related QOL in children and adolescents 2-18 years. A parent proxy-report is available to further
assess health-related QOL for children 2-18 years, whereas the child self-report instrument is available for children 5-18 years. Both parent and child/adolescent report versions were used for the current study. The measure consists of 23 items that form four Generic Core Scales: Physical Functioning \((n = 8)\), Emotional Functioning \((n = 5)\), Social Functioning \((n = 5)\) and School Functioning \((n = 5)\). The authors suggest that results be interpreted in three ways: as a Total Score, a Physical Functioning score, and a Psychosocial Functioning score (a combination of areas of Emotional, Social, and School Functioning). This was the method of analysis chosen for the current study. Disease specific protocols are available for certain illnesses (i.e., cancer, cystic fibrosis, etc.) but not for burn-injured children.

The PedsQL 4.0 is appropriate for use in research, clinical trials, clinical practice, school health settings, and community settings. With regard to validity, the measure successfully distinguishes between healthy children and those with health-related conditions with its indicators of morbidity and illness burden (Varni et al., 2001). For instance, initial development of the instrument involved the assessment of healthy children who visit pediatrician’s offices for well-child appointments and of acutely and/or chronically ill patients who visit one of four hospital specialty clinics (Varni et al., 2001). Children with acute and chronic illness averaged lower scores (thus lower QOL ratings) than did healthy children (as hypothesized). In addition, internal consistency reliabilities exceeded the standard of 0.70 in all subscales, with the exception of the proxy-report for ages 2-4 and self-report for ages 5-7 with regard to the School Functioning Subscales (Varni et al., 2001). The authors recommend that the subscales be used for descriptive and exploratory analysis within the specified domains of functioning (as was done in the current study). With regard to use of the PedsQL in specialty clinics, the measure has proven sensitive enough to detect degrees of disease severity in pediatric cardiology patients and clinical change over time with orthopedics patients (Varni, Seid, Knight, Uzark, & Szer, 2002). In addition, the researchers discovered its potential for impact on clinical decision making in the effort to improve health-related QOL for pediatric patients with rheumatology-related concerns.
(Varni et al., 2002). The creators of the PedsQL intended their measure to remedy the concern that the “new hidden morbidity” in pediatric practice is the under identification of psychosocial concerns; this is done by gaining the perspective of the patient and caregiver regarding physical and psychosocial health concerns (Varni et al., 2002, p. 190).

**Statistical Analyses**

The design used for the current study was correlational: Its aim was to establish the strength of relations among the variables of resilience, QOL, and PTSS and the relations between demographic variables, burn injury characteristics, and PTSS. The abundance of qualitative data collected from each participant allowed for descriptive analysis. This data was used to further explain findings that are related to individual participant demographics, injury characteristics, and overall patient outcome. The current study addressed the following five research questions (as stated in Chapter 1):

1. How are demographic variables (i.e., age, gender, household income, and diagnoses) related to a pediatric burn patient’s PTSS severity?
2. How are burn injury characteristics (i.e., age at burn, time since burn, % TBSA, injury location, surgeries, days spent in hospital) related to a pediatric burn patient’s PTSS severity?
3. How are resilience factors (i.e., sense of mastery, sense of relatedness, and emotional reactivity) related to severity of PTSS?
4. How are QOL outcomes (i.e., physical and psychosocial functioning) related to symptom severity?
5. How are QOL outcomes (i.e., physical and psychosocial functioning) related to resilience?

Descriptive statistics and frequencies were obtained for the demographic and burn injury characteristics of participants and summarized. Additionally, participants were asked to describe the cause of their burn injury within the intake form. These comments were
descriptively analyzed, condensed, and included within a descriptive table alongside participant demographic information. (See results section.)

Some demographic and burn characteristic variables were coded into categories (i.e., child or adolescent, household income above $50,000 or below $50,000, surgery or no surgery) for ease of data analysis, due to lack of variability in the data, and/or small sample size. Research questions 1 and 2 were examined using Pearson correlations for severity of PTSS and continuous variables (i.e., current age, age at burn, time since burn, % TBSA, and days spent in the hospital) and independent sample t-tests for categorical variables (i.e., gender, income, diagnoses and surgery) with severity of PTSS as the dependent variable.

To investigate Question 3 which addresses the protective factors (resiliency) that are related to severity of PTSS, a Pearson correlation was used to assess the relation between the three levels of resiliency (i.e., sense of mastery, sense of relatedness, and emotional reactivity) and PTSS. To investigate questions 4 and 5, Pearson correlations were used to assess the relation between QOL (i.e., physical and psychosocial functioning) and PTSS severity and again to assess the relation between the aforementioned factors of QOL and resilience.
CHAPTER IV
RESULTS

The purpose of the present study was to examine PTSS in children who have sustained a burn injury in relation to resiliency factors and QOL outcome. In examining information provided from children with burn injuries and their parent/caregiver, the following findings represent their estimation of PTSS severity, resiliency and QOL outcome following a burn injury. This section will be organized and presented by ascending order of research questions 1-5. Of note, the participant scores will not be presented in groups of children (ages 9-12) versus adolescents (ages 13-18), as data analyses indicated that there was not a significant difference between groups on any measure (i.e., PTSD Index, RSCA, or PedsQL).

This chapter begins with a description of demographic and burn injury characteristics for each participant as reported on the intake forms, in addition to participant comments describing the burn injury. Following the participant characteristics information, the scale descriptions of the measures used in the current study (i.e., PTSD Index, RSCA, and PedsQL) will be presented, alongside healthy normative population means for comparison. Following the scale descriptions, the specific results for each research question will be presented in detail. Specifically, the results of the t-tests and correlations calculated in order to examine relations among PTSS severity, demographics and burn injury characteristics, three levels of resiliency, and QOL will be reported. All statistical analyses were conducted using the Statistical Package for the Social Sciences, Version 19 (SPSS). The Bonferroni correction was used to control for Type 1 errors as necessary.

Participant Demographics and Burn Injury Characteristics

Each participant and/or caregiver completed an intake form, which provided data regarding demographic variables, burn injury characteristics and comments regarding the
nature of the burn accident. All information gathered from the intake form is presented in Table 2 (participant demographics and description of burn event) and Table 3 (burn injury characteristics), with the exception of household income to protect participant confidentiality.

The sample consisted of 13 males and seven females. Average age of the current study’s population at the time of data collection was 13 years, 3 months (SD = 2 years, 8 months). Household income was evenly distributed, with 10 participants endorsing annual household income below $50,000 and 10 participants endorsing annual household income above $50,000. There was one outlier, with a reported income of above $150,000 annually. All other participants reported incomes between less than $25,000 and $100,000 annually. Regarding diagnoses, 11 participants endorsed at least one diagnosis (i.e., depression, PTSD, ADHD, ODD, anxiety, or cognitive delay), with four endorsing more than one diagnosis. The most common diagnosis cited was ADHD (n = 7).

As noted in Table 3, the average age at time of burn injury was 7 years, 2 months (SD = 4 years, 7 months) and the average time between burn injury and data collection was 5 years, 9 months (SD = 4 years, 5 months). The average percent of TBSA was 18.79% (SD = 15.86%), with an average hospital stay of 16.6 days (SD = 15.24 days). Most participants (n = 14) required surgery, with seven requiring multiple surgeries (M = 2.25, SD = 3.47). See Table 2 for injury descriptions and Table 3 for injury location.

Scale Descriptions

The score results from each of the assessments used in the study (i.e., PTSD Index, RSCA, and PedsQL) are presented in Table 4, which includes healthy normative population results for comparison. The PTSD Index has a continuous scoring scale, although cutoff score and diagnostic criteria requirements are available to provide preliminary diagnostic information indicative of the likelihood of full, partial, or no PTSD diagnosis. Because the purpose of the current study was to examine PTSS severity,
it was used as a continuous measure, with higher scores indicative of more severe PTSS. Refer to Appendix G to view the PTSD Index Score Report form, modeled after PTSD diagnostic criteria in the DSM-IV (APA, 1994). A score of 38 can be used as a cutoff criterion for consideration of PTSD diagnosis (Steinberg et al., 2004); the average score within the current study’s population was 12.37 (SD = 9.26).

As demonstrated within Table 4, the RSCA utilizes a standardized average t-score of 50 (SD = 10) across subscales of Sense of Mastery, Sense of Relatedness, and Emotional Reactivity. Higher scores within areas of mastery and relatedness are indicative of healthy resiliency, while lower scores within the area of emotional reactivity are indicative of healthy resiliency. The current study’s population achieved scores within the average range across subtests.

The PedsQL authors provided healthy population norms, which were obtained from a sample of school-aged children free of significant health concerns and their parents/caregivers (Varni et al., 2001). Higher scores are indicative of better QOL estimation. The participants’ and parent/caregivers’ scores in the current study were within the average range across areas of psychosocial and physical functioning and total score of the combined areas. (See Table 4.)

Research Question 1

The first research question focused on the effect of demographic variables of current age, gender, household income, and diagnoses on PTSS severity. One participant did not complete the UCLA PTSD Index; therefore, there were 19 participants included in analyses that involved the PTSS severity scores. With regard to diagnoses, only ADHD (n = 7) was eligible for statistical analysis due to limited endorsement of other diagnoses. Independent sample t-tests were conducted to evaluate the effect of demographic variables on PTSS severity, and a Bonferroni correction was applied to minimize Type I error (p = .0167).
As shown in Table 5, results of t-tests did not reveal significant effects of demographic variables (i.e., gender, household income, and ADHD diagnosis) on PTSS severity scores. A Pearson correlation was run to investigate the relation between current age at data collection and PTSS severity; significant correlations were not found between the variables. (See Table 6.)

Research Question 2

The purpose of the second research question was to examine the relations between burn injury characteristics (i.e., age at burn, time since burn, % TBSA, injury location, surgeries, days spent in hospital) and PTSS severity. As shown in Table 6, a Pearson correlation was conducted and the burn injury characteristics were not significantly correlated with PTSS severity score. As depicted in Table 5, t-test results also indicated that the presence or absence of surgery did not significantly affect PTSS severity.

Research Question 3

Another Pearson correlation at the .05 level of significance was run to examine the relation between resilience factors (i.e., sense of mastery, sense of relatedness and emotional reactivity) and PTSS severity. Participant t-scores were utilized as subtest scores, in accordance with the RSCA manual suggestions (Prince-Embury, 2007) and compared to the PTSS severity scores. As depicted in Table 7, there was a significant negative correlation between Sense of Relatedness and PTSS severity ($r = -0.49, p < .05$), with higher relatedness scores indicative of lower levels of PTSS severity. There was also a significant positive correlation between Emotional Reactivity and PTSS severity ($r = 0.67, p < .01$), with lower scores indicative of decreased levels of PTSS severity. Additionally, though not significant, there was a weak negative correlation between Sense of Mastery and PTSS severity ($r = -0.44, p = .055$). Between the RSCA subtests, significant intercorrelations were found among all three areas, indicating internal consistency.
Research Question 4

A Pearson correlation was conducted to investigate the relation between QOL and PTSS severity. The Total Score results across Parent and Self (i.e., Child and Adolescent) versions of the PedsQL were compared to the PTSS severity scores. Further, the PedsQL scores within areas of Physical Health Functioning (obtained from the Physical Functioning area score) and Psychosocial Health Functioning (obtained by combining scores from areas of Emotional, Social and School Functioning) were calculated and used to further discriminate the relation between specific areas of QOL and PTSS severity. With regard to the Parent measure, the area of Psychosocial Health Functioning ($r = -0.61$, $p = < .01$) reached significance, demonstrating a negative correlation between Psychosocial functioning and PTSS severity. There were no significant findings between parent ratings of Physical and Total QOL Outcome and PTSS severity. Regarding results of the Self measure, each QOL area reached significance, indicating a negative correlation between Psychosocial Functioning ($r = -0.76$, $p = < .01$), Physical Functioning ($r = -0.49$, $p = < .05$) and Total QOL Outcome ($r = -0.75$, $p = < .01$). These results indicate that lower estimates of QOL are related to increased estimates of PTSS severity. Additionally, nearly all areas of the Parent and Self QOL scores were significantly correlated, with the exception of the Parent ratings of Physical Health Functioning. (See Table 7).

Research Question 5

Similar to Question 4, the fifth research question was intended to examine the relation between QOL outcomes and resilience. Results from a Pearson correlation ($\alpha = .05$) indicated significant positive correlations between areas of Mastery and Relatedness and Parent and Self ratings among all areas of QOL, with the exception of a nonsignificant result between Relatedness and Parent report of Physical Functioning QOL. Further, significant negative correlations were found between the Emotional Reactivity subscale results and Parent and Child ratings of all areas of QOL, with the exception of another
nonsignificant result within the Parent rating of Physical Functioning QOL. These results are further detailed in Table 7.

**Summary**

Regarding participant characteristics, there was a significant presence of ADHD diagnosis reported in the sample. Overall, findings indicated average participant scores across areas of resiliency and average participant and parent scores regarding QOL, with little evidence of elevated posttraumatic stress symptoms present within the sample as a whole. However, significant correlations were found between areas of PTSS severity, resiliency, and QOL. Specifically, participants who report low levels of sense of mastery and relatedness and high levels of emotional reactivity indicate the highest levels of PTSS severity. Participants and parents who endorse a poorer QOL outcome across areas of Psychosocial and Physical Functioning are reporting higher levels of PTSS severity than those who report a more satisfactory QOL outcome. Further, areas of resiliency and QOL are closely correlated, with lower levels of resilience related to poorer QOL.
### Table 2

**Participant Demographics and Burn Injury Description**

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<thead>
<tr>
<th>ID</th>
<th>Sex</th>
<th>Age Now</th>
<th>Diagnoses</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>18.07</td>
<td>Dep, PTSD</td>
<td>Shirt lit on fire with a lighter. Played with gun powder, which ignited and exploded.</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>16.06</td>
<td></td>
<td>Clothing caught on fire by a candle. Played with gun powder, which ignited and exploded.</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>13.09</td>
<td>ADHD</td>
<td>Held a can of gas next to a burn barrel, which caught on fire and blew up in P's arms.</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>15.07</td>
<td>ADHD</td>
<td>Tripped and fell into the edge of a bonfire. Played with a aerosol can and blow torch. Can exploded in P's face.</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>14.05</td>
<td>ADHD</td>
<td>Played with a lighter.</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>17.07</td>
<td>PTSD</td>
<td>Pulled hot cup of coffee off of table.</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>16.10</td>
<td>ADHD, ODD</td>
<td>House fire ensued from dropped cigarette. P was trapped in bedroom.</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>16.01</td>
<td>ADHD</td>
<td>Leaned over lit firework, which exploded in P's face.</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>15.01</td>
<td>ADHD</td>
<td>P got too close to fire from burning cardboard; spark lit clothes on fire.</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>13.00</td>
<td>ADHD</td>
<td>Meningitis of blood, which caused amputation of limbs.</td>
</tr>
<tr>
<td>11</td>
<td>M</td>
<td>14.03</td>
<td>ADHD</td>
<td>Stood too close to propane heater, which lit clothing on fire.</td>
</tr>
<tr>
<td>12</td>
<td>M</td>
<td>12.03</td>
<td>Dep</td>
<td>Tripped over crock pot cord; hot roast and crock pot fell on foot.</td>
</tr>
<tr>
<td>13</td>
<td>M</td>
<td>12.00</td>
<td>ADHD</td>
<td>Fell into campfire with hot coals that had been lit previous night.</td>
</tr>
<tr>
<td>14</td>
<td>F</td>
<td>11.05</td>
<td>ADHD</td>
<td>Pulled self up on wood burning stove when learning to walk.</td>
</tr>
<tr>
<td>15</td>
<td>F</td>
<td>11.00</td>
<td>ADHD</td>
<td>Pulled hot pot of water from stove onto self.</td>
</tr>
<tr>
<td>16</td>
<td>M</td>
<td>10.10</td>
<td>CD, ADHD,</td>
<td>While climbing onto the kitchen counter, clothing ignited from nearby gas stove.</td>
</tr>
<tr>
<td>17</td>
<td>F</td>
<td>9.10</td>
<td>Anx, ODD</td>
<td>Fell into a campfire.</td>
</tr>
</tbody>
</table>

Note: Range of current age: 9.08–18.07; M ± SEM = 13.3±2.75. Dep = depression; PTSD = posttraumatic stress disorder; ADHD = attention deficit hyperactivity disorder; ODD = oppositional defiant disorder; Anx = anxiety; CD = cognitive delay.
<table>
<thead>
<tr>
<th>ID</th>
<th>Age Burn</th>
<th>Since Burn</th>
<th>%TBSA</th>
<th>Location</th>
<th>In Hospital</th>
<th>Surgeries</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3.11</td>
<td>14.08</td>
<td>43</td>
<td>T, H</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>2</td>
<td>8.06</td>
<td>8.00</td>
<td>55</td>
<td>U, T, L</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4.09</td>
<td>9.00</td>
<td>46</td>
<td>H, U, T</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>14.02</td>
<td>1.05</td>
<td>27</td>
<td>T, U, L</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>12.05</td>
<td>1.02</td>
<td>10</td>
<td>L</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>13.07</td>
<td>0.10</td>
<td>15</td>
<td>H, U</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>14.07</td>
<td>3.00</td>
<td>25</td>
<td>H, U</td>
<td>41</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>0.10</td>
<td>16.03</td>
<td>10</td>
<td>L</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>9.11</td>
<td>6.01</td>
<td>15</td>
<td>H, U, T, L</td>
<td>30</td>
<td>2</td>
</tr>
<tr>
<td>10</td>
<td>13.07</td>
<td>1.06</td>
<td>5</td>
<td>H</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>5.00</td>
<td>9.03</td>
<td>10</td>
<td>T</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>12</td>
<td>5.11</td>
<td>6.04</td>
<td>15</td>
<td>U, L</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>10.07</td>
<td>2.05</td>
<td>9</td>
<td>U, T</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>14</td>
<td>9.03</td>
<td>1.02</td>
<td>5</td>
<td>L</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>7.11</td>
<td>4.01</td>
<td>5</td>
<td>L</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>16</td>
<td>0.11</td>
<td>10.06</td>
<td>1</td>
<td>U</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>17</td>
<td>2.00</td>
<td>9.00</td>
<td>5</td>
<td>H, U</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>18</td>
<td>6.11</td>
<td>3.10</td>
<td>6</td>
<td>U, T</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>19</td>
<td>3.04</td>
<td>6.06</td>
<td>30</td>
<td>H, U, T, L</td>
<td>30</td>
<td>15</td>
</tr>
<tr>
<td>20</td>
<td>2.02</td>
<td>7.06</td>
<td>30</td>
<td>U, L</td>
<td>7</td>
<td>0</td>
</tr>
</tbody>
</table>

Range .10-14.07 .10-16.03 1-55 1-50 0-15
M±SEM 7.02±4.65 5.84±4.50 18.79±15.86 16.6±15.24 2.25±3.47

Note: Age and Since Burn represented as YY.MM. %TBSA= percent of burn surface area; Location = area of the body burned; T = Torso; H = Head; U = Upper Extremity; L = Lower Extremity.
Table 4

*Scale Descriptive of PTSS, Resiliency, and QOL Across Participants and Normative Population*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Healthy Norm</th>
<th>M</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PTSD Index</strong></td>
<td>continuous scale(^a)</td>
<td>12.37</td>
<td>9.26</td>
<td>2</td>
<td>38</td>
</tr>
<tr>
<td><strong>RSCA</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAS</td>
<td></td>
<td>52.05</td>
<td>10.94</td>
<td>35</td>
<td>70</td>
</tr>
<tr>
<td>REL</td>
<td></td>
<td>50.55</td>
<td>8.56</td>
<td>35</td>
<td>66</td>
</tr>
<tr>
<td>REA</td>
<td></td>
<td>50.35</td>
<td>12.47</td>
<td>32</td>
<td>78</td>
</tr>
<tr>
<td><strong>Parent PedsQL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychsoc</td>
<td></td>
<td>80.58</td>
<td>16.52</td>
<td>35</td>
<td>100</td>
</tr>
<tr>
<td>Phys</td>
<td></td>
<td>81.38</td>
<td>23.18</td>
<td>25</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>80.87</td>
<td>16.73</td>
<td>45.65</td>
<td>98.91</td>
</tr>
<tr>
<td><strong>Self PedsQL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychsoc</td>
<td></td>
<td>79.37</td>
<td>15.70</td>
<td>48.33</td>
<td>100</td>
</tr>
<tr>
<td>Phys</td>
<td></td>
<td>80.19</td>
<td>19.30</td>
<td>78.13</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>79.62</td>
<td>15.26</td>
<td>58.7</td>
<td>98.91</td>
</tr>
</tbody>
</table>

Note: PTSS = posttraumatic stress symptoms; MAS = Sense of Mastery; REL = Sense of Relatedness; REA = Emotional Reactivity; PedsQL = Pediatric Quality of Life; Psychsoc = Psychosocial Health Functioning; Phys = Physical Health Functioning; Total = Total score

\(^a\)The UCLA PTSD Index is a continuous scale with cutoff score and diagnostic criteria requirements which indicate the likelihood of full, partial, or no PTSD diagnosis. No participants met *full PTSD diagnosis likely*, while one met *partial PTSD likely*

\(^b\)Represents \(t\)-score \((x = 50, SD = 10)\).
Table 5

*Results of t-tests of PTSS Severity versus Sex, Income, ADHD & Surgery*

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>PTSS Score</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>14.77 (9.78)</td>
<td>1.76</td>
<td>0.097</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>7.17 (5.64)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below $50K</td>
<td></td>
<td>12.11 (6.95)</td>
<td>0.112</td>
<td>0.912</td>
</tr>
<tr>
<td>Above $50K</td>
<td></td>
<td>12.60 (11.34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>14.43 (13.66)</td>
<td>0.731</td>
<td>0.475</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>11.17 (5.86)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>12.85 (9.31)</td>
<td>0.323</td>
<td>0.751</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>11.33 (9.96)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Results of a Bonferroni correction indicate significance level at p < .0167. ADHD = attention deficit hyperactivity disorder

Table 6

*PTSS Severity: Correlations with current age and burn injury characteristics*

<table>
<thead>
<tr>
<th>Age</th>
<th>Age Burn</th>
<th>Since Burn</th>
<th>%TBSA</th>
<th>In Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>-0.08</td>
<td>0.06</td>
<td>-0.13</td>
<td>0.11</td>
<td>0.12</td>
</tr>
</tbody>
</table>
Table 7

*Intercorrelations between PTSS Severity, Resiliency, and Parent/Self QOL*

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PTSS</td>
<td>—</td>
<td>-.44</td>
<td>-.49*</td>
<td>.67**</td>
<td>-.61**</td>
<td>.06</td>
<td>- .42</td>
<td>-.76**</td>
<td>-.49*</td>
<td>-.75**</td>
</tr>
<tr>
<td>RSCA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. MAS</td>
<td>—</td>
<td>.81**</td>
<td>-.66**</td>
<td>.72**</td>
<td>.49*</td>
<td>.76**</td>
<td>.76**</td>
<td>.73**</td>
<td>.81**</td>
<td></td>
</tr>
<tr>
<td>3. REL</td>
<td>—</td>
<td>-.65**</td>
<td>.65**</td>
<td>.42</td>
<td>.68**</td>
<td>.80**</td>
<td>.61**</td>
<td>.86**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. REA</td>
<td>—</td>
<td>-.71**</td>
<td>-.03</td>
<td>-.56*</td>
<td>-.74**</td>
<td>-.60**</td>
<td>-.74**</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Parent PedsQL</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Psychsoc</td>
<td>—</td>
<td>.39</td>
<td>.91**</td>
<td>.70**</td>
<td>.72**</td>
<td>.75**</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6. Phys</td>
<td>—</td>
<td>.71**</td>
<td>.18</td>
<td>.44</td>
<td>.25</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Total</td>
<td>—</td>
<td>.59**</td>
<td>.69**</td>
<td>.66**</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Self PedsQL</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Psychsoc</td>
<td>—</td>
<td>.62**</td>
<td>.99**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Phys</td>
<td>—</td>
<td>.75**</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10. Total</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: PTSS = posttraumatic stress symptoms; MAS = Sense of Mastery; REL = Sense of Relatedness; REA = Emotional Reactivity PedsQL = Pediatric Quality of Life; Psychsoc = Psychosocial Health Functioning; Phys = Physical Health Functioning; Total = Total score.

* *p < 0.05 (2-tailed) ** p < 0.01 level (2-tailed).*
CHAPTER V
DISCUSSION AND CONCLUSIONS

This section will begin with a brief discussion related to the purpose of the study, followed by the findings of the research questions with respect to the relation between PTSS severity, resiliency, and QOL in comparison to findings of previous research. Next, implications and limitations of the study will be discussed. The chapter concludes with suggestions for future research.

Discussion

The current study examined the factors that are related to a pediatric burn patient’s psychological outcome, specifically, with regard to the development of PTSS. Participants and their parents completed questionnaires related to the following areas: (a) demographics and burn injury circumstances; (b) PTSS related to burn injury; (c) resiliency, as related to a sense of mastery, relatedness, and emotional reactivity; and (d) QOL, which involves physical and psychosocial functioning. The results of the resiliency and QOL questionnaires were measured and compared across participants in relation to their appraisal of PTSS.

Research Question 1

In accordance with previous findings (Allen & Kagan, 2004; Drago, 2005), males (65%) represented a larger portion of the sample than did females. Current age was not found to be correlated with PTSS severity; however, as suggested in the literature, age at time of burn is typically more closely related to PTSS severity (Daviss et al., 2000; Le Brocque et al., 2009).

A significantly greater portion of the current study’s population endorsed having a diagnosis of ADHD (35%); this finding is different from that of the 3-7% found in school-aged children as estimated in the DSM-IV (APA, 1994). The discovery that burn
injuries occur at a higher rate in children with ADHD has been supported previously (Ghanizadeh, 2008). Further, ADHD is more prevalent in males (APA, 1994), which parallels the disproportionate gender distribution found in the current study. A study by Pardo and colleagues (2008) indicated that children with burn injuries demonstrate a higher incidence of attention and behavioral disorders in the short- and long-term aftermath of the injury. In the current study, it is unknown when the ADHD diagnosis was made and whether it was a precursor to or product of the burn injury or whether it was unrelated. Although significant psychopathology has been linked to burn injury in children and adolescents (Davydow et al., 2009; Stoddard et al., 1989), the data from the current study did not indicate high rates of comorbid diagnoses, with the exception of ADHD. This finding is in accordance with the relatively healthy participant results found across measures.

Another demographic variable of interest was household income. Prince-Embury (2009) indicated that parent education level is related to resiliency factors in children. Although parent education level was not a variable of analysis in the current study, household income is positively correlated with education level. Post-hoc analysis was conducted regarding a relation between income and resiliency. A Pearson correlation indicated that Sense of Mastery ($r = .45, p = <.05$) and Sense of Relatedness ($r = .47, p = <.05$) were significantly positively correlated with household income, whereas Emotional Reactivity was not found to be significantly related to resiliency. See Table 1 for descriptions of areas of resiliency.

Research Question 2

As suggested by several studies (Drago, 2005; Dissanaike & Rahimi, 2009; Istre et al., 2002), burn injuries typically occur in children below age five. In the current study, the average age at time of burn was slightly older at 7 years, 1 month. Further, although younger children typically fare better postburn injury (Daviss et al., 2000; Le Brocque et
al., 2009), age at time of burn was not significantly correlated with PTSS severity. This finding may be attributed to low sample size. Further, analysis of the correlation between developmental age and symptom trajectory was not possible, due to the time lapse between the burn incident and data collection.

Contrary to previous findings which have indicated a correlation between number of invasive procedures (Bronner et al., 2008) and duration of hospitalization (Jones et al., 1992) with regard to PTSS severity, the current study did not support those findings. Participants also did not endorse a relation between percent of TBSA, injury location, and PTSS severity. As expected, percent TBSA and duration of hospitalization were significantly correlated. Overall, burn injury characteristics were not significantly related to PTSS severity, which may be attributed to a limited sample size.

Another interesting finding relates to the etiology of the burn injuries experienced by the participants. Although it is estimated that 6-20% of child abuse is caused by burning (Peck & Priolo-Kapel, 2002), there were no reported instances of intentional child abuse within the current study’s population. A rational hypothesis regarding the absence of child abuse in the sample could be consideration of a sampling bias. Specifically, a parent/caregiver who has been investigated or prosecuted for child abuse is less likely to participate in research related to a child’s injury.

With regard to injury descriptions, the participants endorsed a variety of incidents leading to their burn injuries. Only one participant reported involvement of another individual in the event, and no one indicated any loss of life. It is plausible to consider that the PTSS severity findings may have demonstrated more significant psychopathology if other individuals had been harmed or perished as a result of the burn incident. Refer to Table 2 in the results section for descriptions of the burn injuries, which were condensed from participant comments on the intake form.
Research Question 3

A significant finding of the study—and one of the most crucial—was the correlation between PTSS and areas of resilience related to sense of relatedness and emotional reactivity. As defined by Weiss (2008) and implemented within the RSCA definitions of resilience (Prince-Embury, 2007), relatedness involves trust (i.e., ability to receive and accept what is given); access to support (i.e., perceived access to support as based upon underlying trust in relatedness); social comfort (i.e., temperamental differences in comfort with others); and tolerance of differences (i.e., the ability to have one’s own thoughts and express them even though they may be different from the thoughts of others). The findings of the study indicate that there is a negative relationship between these areas of relatedness and a burn injury survivor’s experience of PTSS. In other words, high levels of trust, access to support, social comfort, and tolerance of differences are related to a more successful outcome regarding experience of PTSS after burn injury.

Concurrently, emotional reactivity involves sensitivity (i.e., speed and intensity of a child’s negative emotional responses); recovery (i.e., self-regulation from intense emotion); and impairment (i.e., the level of impairment of function due to emotional arousal; Weiss, 2008). The participants in the current study indicated that low levels of emotional reactivity translate to lower levels of PTSS severity. These findings are open to interpretation, because it is unclear whether the factors of relatedness and emotional reactivity are a by-product of the traumatic burn injury event or whether they were protective factors that are present within the child prior to the event.

The finding that sense of mastery (i.e., optimism, self-efficacy and adaptability) was only weakly correlated with PTSS severity is also open to interpretation. Of the three areas of resilience, mastery seems to be the most internally driven factor, as opposed to relatedness and reactivity, which are more closely related to or reliant upon the behavior or response to behavior of others. Perhaps this finding, relevant to the internal nature of
mastery, indicates that the experience of PTSS can be influenced by outside forces more so than internally driven or altered. Because social support is a factor in the experience of psychopathology, the fact that conceptualization of relatedness and emotional reactivity are more prevalent resiliency factors than mastery (regarding PTSS severity) makes sense. These considerations may be an avenue for future debate.

Research Question 4

Similar to previous research indicating an increased risk of impairment in overall QOL for burn injured children who have diagnoses of PTSD (Landoldt, 2009), results of this study indicated a relation between QOL outcomes and PTSS severity. However, overall QOL outcomes were similar to those reported by peers of the same age.

In particular, children and adolescents who endorsed higher ratings of PTSS severity also indicated relative difficulty within areas of physical and psychosocial (i.e., school, emotional, and social functioning). Parents’ estimations of psychosocial functioning were related to PTSS severity, but physical functioning was not. This finding was similar with regard to the parent QOL ratings in comparison to resilience and will be discussed further.

Overall, these findings indicate that children with burn injuries who experience increased rates of PTSS may also experience deterioration of QOL, a finding that is echoed by previous research (Landoldt et al., 2009). However, the results of the QOL measure indicate an overall QOL comparable to the healthy normative population; this is in agreement with other studies finding positive QOL outcome in children with burn injuries (Herndon, 1986; Landoldt, et al., 2002; Pope et al., 2007; Sheridan et al, 2000). It is unclear as to what the specific differences are within the population that experiences higher rates of PTSS that affect QOL outcome.
Research Question 5

Findings of the current study indicate that, although the overall QOL outcomes were comparable to those experienced by healthy, same-aged peers, there was a correlation between QOL and resilience. These results are in accordance with the findings by Holaday and Terrell (1994), which indicated higher self-esteem, better interpersonal skills, more cooperation, and better tolerance and overall coping within resilient children, in comparison to nonresilient children. Similarly, higher rates of physical, emotional, social, and school functioning were found in the current study’s population who endorsed higher rates of resilience. This may be a cyclical pattern, in that it is difficult to determine causation between resilience and QOL. While there is a significant relation between the two variables, results in the current study indicate that there is no evidence of whether a strength within one variable caused the other to increase.

Interestingly, the one area of nonsignificance within the QOL ratings in comparison to resilience and PTSS severity was within the parents’ estimates of their child’s physical functioning in relation to sense of relatedness and emotional reactivity. This finding is intriguing, considering that physical functioning is perhaps the most outwardly presented and apparent area of functioning that is easily observable to an outside viewer. An explanation of this finding may be that the overlap in definition that is related to psychosocial factors and resilience. The concept of resilience is more closely related to psychosocial aspects than physical functioning concerns. Because resilience was found to be highly correlated with PTSS, it is not surprising that psychosocial QOL concerns are significantly related to resilience. Further, although the parent and child physical functioning ratings were not correlated, both the parent and child ratings were within average to high average range in comparison to what was reported within the healthy normative sample.
Implications

The findings of the current study provide multiple implications for assessment of PTSS following pediatric burn injury. As indicated by the elevated rate of ADHD endorsed by the current study’s participants, it may be worthwhile for clinicians to assess for ADHD symptoms when encountering a child who has sustained a burn injury. Since there is a greater likelihood that ADHD symptoms are present within a burn-injured child (Ghanizadeh, 2008), identification of impulsive behavior concerns could potentially lead to necessary intervention to prevent future symptom-related threats to well-being.

With regard to clinical implications, the significant correlation between resilience and PTSS indicates the importance of evaluating and strengthening resilience in children who have sustained burn injuries. Although the scope of this study was exploratory in nature—with an overall goal of identifying relationships between PTSS and resilience, consideration of intervention is a crucial next step toward building the areas of resilience in children with burn injuries and adolescents who do not naturally possess such characteristics. The findings of the current study indicate that resilience is an important factor to consider when care to a child or adolescent who has sustained a burn injury is provided; this potentially leads to a decreased likelihood of PTSS and increased probability for positive QOL outcome.

Overall results of the current study suggest that there may be a relation between PTSS, resiliency, and QOL, which indicates the potential for pediatric burn survivors to have positive outcomes after burn injury, because overall ratings were similar to healthy peers. Although parent coping and adjustment that follow a burn injury can be negative and at best an emotionally volatile process, it may be valuable to share positive outcome statistics with children at their time of stress, guilt, and anxiety regarding the future (Pope et al., 2007).
Study Limitations

There are limitations to the current study requiring that the results be interpreted with caution. The most critical limitation is low sample size, which results in an inability to utilize more sophisticated statistical analysis and severely limits power. One hypothesis for low participation rate for the burn camp attendees was time required to complete the questionnaires. Many of the parent/caregivers and/or children asked about the requirements and were subsequently uninterested in participation, citing a greater desire to begin the festivities of the check-in evening. The data collection tables were located just outside of the gymnasium and campers had visual and auditory access to the goings-on in the adjacent gymnasium. A second hypothesis regarding low participation rate for burn camp attendees is an unwillingness to complete measures about a sensitive topic. Several parents made comments to the researcher indicative of a fear of exposure to a potentially sensitive topic, citing recency of burn injury or difficulty with adjustment related to the burn injury. As such, it is plausible to hypothesize that the campers who chose not to participate may have endorsed higher PTSS severity ratings and/or lower QOL and resiliency ratings.

With regard to clinical implications, one must note that the participants were being screened for posttraumatic stress symptoms rather than for posttraumatic stress disorder. It is unclear whether the results would be as applicable to patients who meet the criteria for PTSD and what those differences would be, if any. Additionally, because of the lapse in time between acquisition of the participants’ burn injuries and data collection, there is no way of determining the acute PTSS that were present immediately following the burn injury. This time lapse affects clinical implications, because the ideal window for assessing and treating psychological consequences of burn injuries is immediately following the injury. Research has indicated that approximately 30% of children meet the criteria for PTSD at some point within six months following a burn injury; the average time since burn in the sample was approximately five years for the current study.
Areas for Future Research

Considering the dearth of research available within the area of PTSS and pediatric burn injuries, several avenues of future research are warranted.

A longitudinal study, beginning with intake immediately following the burn injury and following the participant for a year or more, would contribute to our knowledge of how PTSS, resiliency, and quality of life change over time in burned children and adolescents. This longitudinal research could help inform treatment practices, because it may be the case that children with different burn injury characteristics and demographic variables respond discrepantly to intervention. Because age has been shown to be correlated with symptom trajectory (Le Brocque et al., 2009), a longitudinal study would need to be performed with participants of varying ages to accurately assess resiliency factors in a developmentally appropriate manner.

As the current study suggested, resilience is correlated with PTSS severity, even in the long-term aftermath following a burn injury. Creation of a resilience strengthening intervention would be a useful strategy for clinicians to use within their arsenal of treatments for children and adolescents who have experienced a burn injury and who are subsequently at risk for development of PTSS or other long-term complications that lead to comorbid diagnoses. Research is warranted to investigate the window of resilience strengthening strategies that would serve to decrease symptoms of PTSS or to prevent their occurrence altogether. The findings of this study suggest that the reduction of PTSS and strengthening of resilience have positive effects of QOL, which is perhaps the most socially relevant outcome of this research.
REFERENCES


McHorney, C. A., Ware, J. E., Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36), II. *Medical Care, 31*, 247-263.


APPENDIX A. COVER LETTER FOR BURN CAMP PARTICIPANTS

Sarah Powers, M.A.
c/o Tammy L. Wilgenbusch, Ph.D.
100 Hawkins Drive, 140-C CDD
University of Iowa Children’s Hospital
Division of Pediatric Psychology
Iowa City, Iowa 52242

Dear Sir or Madame:

We are writing to invite your child to participate in a research study. The purpose of the study is to investigate how stress symptoms related to burn injuries are influenced by resiliency (or, the protective factors that allow an individual to cope with stress) and the circumstances of the burn injury (i.e., total body surface area injured, the nature of the injury, location of the injury, length of hospital stay, etc.). This information is important because little is known about the functioning of children and adolescents following a burn injury. A better understanding of this may help to improve burn treatment.

We are inviting your child to participate in this research study because he/she has sustained a burn injury and is between the ages of 9-17. We obtained your name and address through the mailing list for the Burn Camp.

If you agree for your child to participate in this study, we ask that you review the consent form and intake sheet, which are enclosed within this packet of information. Please bring the consent form and intake sheet to Burn Camp. Upon check-in, the study will be explained to you and your child, any questions will be answered and, if interested in participation, you will consent and s/he will assent indicating your willingness to participate. You will complete the intake form. Your child will complete two questionnaires. One is a measure of an individual’s sense of mastery (i.e., optimism, self-efficacy, and adaptability), sense of relatedness (trust, support, comfort, and tolerance), and emotional reactivity (sensitivity, recovery, and impairment). The other will assess possible symptoms of traumatic stress related to the burn. The questionnaires will take approximately 10-15 minutes of your child’s time. You may skip any question on the intake form and your child may skip any question on the questionnaires you do not wish to answer. There will be no responsibility following the completion of the questionnaires at Burn Camp check-in.

If you have any questions about the research study, please contact: Sarah Powers or Tammy Wilgenbusch; University of Iowa Children’s Hospital, 100 Hawkins Drive, 140-C Center for Disabilities and Development, Iowa City, IA 52242; 319-384-9977.

Thank you very much for your consideration.

Sincerely,

Sarah Powers, M.A., Primary Investigator
Pre-Doctoral Intern, Pediatric Psychology
APPENDIX B. INTAKE/DEMOGRAPHICS FORM

Parent/Guardian: Please provide the following information about your child. Thank you.

Child's Date of Birth: __________________________

Child's Gender: ______ Male ______ Female

Your Approximate Annual Household Income (Please Check One):

____ Under $25,000
____ $25,000-$50,000
____ $50,000-$75,000
____ $75,000-$100,000
____ $100,000-$150,000
____ More than $150,000

Please indicate any conditions your child may have been diagnosed with. Check all that apply.

____ Cognitive Delay
____ Attention Deficit-Hyperactive Disorder (ADHD)
____ Depression
____ Anxiety
____ Posttraumatic Stress Disorder (PTSD)
____ Oppositional Defiant Disorder (ODD)/Conduct Disorder
____ Other (Please Specify): __________________________

Approximate Date Child's Burn Injury Occurred (Month/Year): ________________

Total Body Surface Area Injured: ________%

Location of Burn Injury: __________________________

Number of Surgeries Related to the Burn Injury: ____________

Number of Days Spent in the Hospital Following the Burn Injury: ____________

Were other individuals injured as a result of the incident? ______ *Yes ______ No

*If yes, please explain (how many individuals were injured, and their relationship with your child):

(OVER)
Please provide a brief description of how the burn occurred:

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________

________________________________________
APPENDIX C. INFORMED CONSENT FORM

INFORMED CONSENT DOCUMENT

Project Title: Resiliency and post-traumatic stress symptoms in burn injured children and adolescents

Principal Investigator: Sarah Powers

Research Team Contact: Tammy Wilgenbusch – 319-384-9977

- If you are the parent/guardian of a child under 18 years old who is being invited to be in this study, the word “you” in this document refers to your child. You will be asked to read and sign this document to give permission for your child to participate.
- If you are a teenager reading this document because you are being invited to be in this study, the word “you” in this document refers to you. You will be asked to read and sign this document to indicate your willingness to participate.

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

- If you have any questions about or do not understand something in this form, you should ask the research team for more information.
- You should discuss your participation with anyone you choose such as family or friends.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We are inviting you to participate in this research study because you sustained a burn injury.

The purpose of this research study is to investigate how stress symptoms related to burn injuries are influenced by resiliency (or, the protective factors that allow an individual to cope with stress) and the circumstances of the burn injury (i.e., total body surface area injured, the nature of the injury, location of the injury, length of hospital stay, etc.). This information is important because little is known about the functioning of children and adolescents following a burn injury. A better understanding of this may help to improve burn treatment.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 100 people will take part in this study conducted by investigators at the University of Iowa.
HOW LONG WILL I BE IN THIS STUDY?

- If you agree to take part in this study, your involvement will last for approximately 10-15 minutes, or the time it takes to complete our questionnaires.

WHAT WILL HAPPEN DURING THIS STUDY?

If you agree to participate in this study, you will complete the questionnaires provided by the researcher at Burn Camp check-in. You will complete one questionnaire that measures an individual’s sense of mastery (i.e., optimism, self-esteem, competence, and adaptability), sense of relatedness (trust, support, comfort, and tolerance), and emotional reactivity (sensitivity, recovery, and impairment). You will also complete another questionnaire, which will assess possible symptoms of traumatic stress related to your burn. You may skip any question on either questionnaire you do not wish to answer.

Upon collecting and processing your completed questionnaires and signed consent form, we will collect information related to your burn injury from your hospital record with your approval. Specifically, we will obtain your age (per birth date), gender, date of burn injury, how you sustained your injury, the location of your injury, and other information related only to your burn injury. Your parent will be asked to answer a brief set of questions about you. If you do not wish your medical record to be reviewed, your parent will be asked to answer a few further questions about your burn injury.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

You may feel uncomfortable answering some of the questions. If this occurs, you may skip the question. There is a risk of loss of confidentiality. Measures in place to protect confidentiality are in the ‘What About Confidentiality?’ section later in this document.

WHAT ARE THE BENEFITS OF THIS STUDY?

We don’t know if you will benefit from being in this study. However, we hope that, in the future, other people might benefit from this study because the knowledge that will be gained may help with future social-emotional treatment of burn injuries.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will not be paid for being in this research study.
WHO IS FUNDING THIS STUDY?

The University and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

WHAT ABOUT CONFIDENTIALITY?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, you will be assigned a subject ID number. Only the Principle Investigator and research delegates will have access to your name and subject ID number. All information will be stored electronically in a password protected file on a secure server. Hard copies of your questionnaires will be stored in a locked file cabinet in a locked office within the Division of Pediatric Psychology. Only members of the research team will have access to data identified by subject ID numbers. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

WILL MY HEALTH INFORMATION BE USED DURING THIS STUDY?

The Federal Health Insurance Portability and Accountability Act (HIPAA) requires your health care provider to obtain your permission for the research team to access or create "protected health information" about you for purposes of this research study. Protected health information is information that personally identifies you and relates to your past, present, or future physical or mental health condition or care. We will access health information about you, as described in this document, for purposes of this research study. Once your health care provider has disclosed your protected health information to us, it may no longer be protected by the Federal HIPAA privacy regulations, but we will continue to protect your confidentiality as described under "Confidentiality."

Giving the research team permission to access your health information is optional. Please initial your choice below.

______ Yes, the research team may access my health information for this study and my signature on this consent document authorizes the research team to do so.

______ No, the research team may NOT access my health information.
We may share your health information related to this study with the University of Iowa Institutional Review Boards and support staff.

Although you may not be allowed to see study information until after this study is over, you may be given access to your health care records by contacting your health care provider. Your permission for us to access or create protected health information about you for purposes of this study has no expiration date. You may withdraw your permission for us to use your health information for this research study by sending a written notice to Sarah Powers or Tammy Wilgenbusch; University of Iowa Children’s Hospital, 100 Hawkins Drive, 140-C Center for Disabilities and Development, Iowa City, IA 52242. However, we may still use your health information that was collected before withdrawing your permission. Also, if we have sent your health information to a third party, such as the study sponsor, or we have removed your identifying information, it may not be possible to prevent its future use. You will receive a copy of this signed document.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won’t be penalized or lose any benefits for which you otherwise qualify.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Sarah Powers or Tammy Wilgenbusch at: (319) 384-9977. If you experience a research-related injury, please contact: Sarah Powers or Tammy Wilgenbusch at: (319) 384-9977.

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, or e-mail hbo@uiowa.edu. General information about being a research subject can be found by clicking “Info for Public” on the Human Subjects Office web site, http://research.uiowa.edu/hso. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.
This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject’s Name (printed):

Do not sign this form if today’s date is on or after EXPIRATION DATE: 06/22/21.

(Signature of Subject) (Date)

Parent/Guardian or Legally Authorized Representative’s Name and Relationship to Subject:

(Name - printed) (Relationship to Subject - printed)

Do not sign this form if today’s date is on or after EXPIRATION DATE: 06/22/21.

(Signature of Parent/Guardian or Legally Authorized Representative) (Date)

Statement of Person Who Obtained Consent

I have discussed the above points with the subject or, where appropriate, with the subject’s legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

(Signature of Person who Obtained Consent) (Date)
APPENDIX D. ASSENT FORM

ASSENT DOCUMENT

Project Title: Resiliency and Post-Traumatic Stress symptoms in burn injured children and adolescents
Investigator(s): Sarah Powers, MA

We are doing a research study. A research study is a special way to find out about something. We are trying to find out what things help children and teens feel safe and happy after they have been burned.

If you decide that you want to be in this study, this is what will happen. Your parent or caregiver will fill out some forms that give us information about you and your burn injury. You will fill out two forms that tell about how you feel after you were burned and how you feel in general. You won’t have to do anything else after you fill out the two forms. They will take about 15 minutes of your time. We will also collect information from your medical record.

We want to tell you about some things that might hurt or upset you if you are in this study. You might feel a little upset answering questions about your burn injury. You don’t have to answer all of the questions if you choose not to. We are here if you have questions.

We don’t know if being in this research study will help you. But we hope to learn something that will help other people some day.

When we are done with the study, we will write a report about what we found out. We won’t use your name in the report.

You don’t have to be in this study. It’s up to you. If you say okay now, but you change your mind later, that’s okay too. All you have to do is tell us.

If you want to be in this study, please sign or print your name.

I, ____________________________, want to be in this research study.

(Child’s name)

__________________________  __________________________
(Sign or print your name here)  (Date)
APPENDIX E. COVER LETTER FOR MAILER PARTICIPANTS

Sarah Powers, M.A.
c/o Tammy L. Wilgenbusch, Ph.D.
100 Hawkins Drive, 140-C CDD
University of Iowa Children’s Hospital
Division of Pediatric Psychology
Iowa City, Iowa 52242

Dear Sir or Madame:

We are writing to invite your child to participate in a research study. The purpose of the study is to investigate how stress symptoms related to burn injuries are influenced by resiliency (or, the protective factors that allow an individual to cope with stress) and the circumstances of the burn injury (i.e., total body surface area injured, the nature of the injury, location of the injury, length of hospital stay, etc.). We are also interested in gathering information regarding the quality of life in children and adolescents who have sustained a burn injury. This information is important because little is known about the functioning of children and adolescents following a burn injury. A better understanding of this may help to improve burn treatment.

We are inviting your child to participate in this research study because your child or adolescent sustained a burn injury and is between the ages of 9-17. We obtained your name and address through the Burn Treatment Center mailing list. Approximately 130 people will take part in this study at the University of Iowa.

If you agree for your child to participate in this study, we ask that you and your child complete the enclosed intake sheet and questionnaires, which are included within this packet of information. You will complete the intake form and a questionnaire (Pediatric Quality of Life: Parent Form). Your child will complete three questionnaires. One (Resiliency Scales for Children and Adolescents) is a measure of an individual’s sense of mastery, sense of relatedness, and emotional reactivity. The other (The UCLA PTSD Index) will assess possible symptoms of traumatic stress related to the burn. The third will assess quality of life (Pediatric Quality of Life: Child Form). The questionnaires will take approximately 15-25 minutes of your child’s time. You and your child may skip any question you do not wish to answer.

Please complete the forms and return them within the enclosed self-addressed, stamped envelope within two weeks of receipt. There will be no responsibility following the completion and return of the questionnaires. By returning the completed forms, you will become eligible for a drawing to win one of two available $25 Target gift cards. We will not contact you again if we receive no response.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. A subject ID number is on the enclosed questionnaires. The only link to your name is from the original mailing list,
which will be destroyed upon mailing the Target gift cards. Your data will be unlinked from your name. If we write a report about this study we will do so in such a way that you cannot be identified. The questionnaires will be stored in a way to protect subject confidentiality.

There are no known risks from being in this study, and you will not benefit personally. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study.

You may be paid for being in this research study. You will be eligible to win a $25 Target gift card upon receipt of the enclosed materials. Two people among those enrolled will receive a gift card.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won’t be penalized or lose any benefits for which you otherwise qualify.

If you have any questions about the research study itself, please contact: Sarah Powers or Tammy Wilgenbusch; University of Iowa Children’s Hospital, 100 Hawkins Drive, 140-C Center for Disabilities and Development, Iowa City, IA 52242; 319-384-9977. If you experience a research-related injury, please contact: Sarah Powers or Tammy Wilgenbusch, 319-384-9977. If you have questions about the rights of research subjects, please contact the Human Subjects Office, Hardin Library for the Health Sciences, 600 Newton Road, University of Iowa, Iowa City, IA 52242-1096, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

Thank you very much for your consideration. Completing and returning these questionnaires will indicate your and your child’s/adolescent’s willingness to participate in the study.

Sincerely,

Sarah Powers, M.A., Primary Investigator
Pre-Doctoral Intern
Pediatric Psychology
APPENDIX F. RESILIENCY SCALES FOR
CHILDREN AND ADOLESCENTS (RSCA)

The RSCA is a copyrighted material. Therefore, this instrument will not be included in this appendix.
APPENDIX G. UCLA PTSD REACTION INDEX FOR DSM-IV:
CHILD AND ADOLESCENT VERSIONS AND SCORING SHEET
FOR THE FOLLOWING QUESTIONS, please CHECK [YES] or [NO] to answer HOW YOU FELT during or right after being burned.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>15) Were you scared that you would die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16) Were you scared that you would be hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17) Were you hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18) Were you scared that someone else would die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19) Were you scared that someone else would be hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20) Was someone else hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21) Did someone die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22) Did you feel very scared, like this was one of your most scary experiences ever?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>23) Did you feel that you could not stop what was happening or that you needed someone to help?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>24) Did you feel that what you saw was disgusting or gross?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25) Did you run around or act like you were very upset?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26) Did you feel very confused?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27) Did you feel like what was happening did not seem real in some way, like it was going on in a movie instead of real life?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Here is a list of problems people sometimes have after very bad things happen. Please THINK about being burned. Then, READ each problem on the list carefully. CIRCLE ONE of the numbers (0, 1, 2, 3 or 4) that tells how often the problem has happened to you in the past month. Use the Rating Sheet on Page 5 to help you decide how often the problem has happened in the past month.

**PLEASE BE SURE TO ANSWER ALL QUESTIONS**

<table>
<thead>
<tr>
<th>HOW MUCH OF THE TIME DURING THE PAST MONTH</th>
<th>None</th>
<th>Little</th>
<th>Some</th>
<th>Much</th>
<th>Most</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I watch out for danger or things that I am afraid of.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. When something reminds me of what happened, I get very upset, afraid or sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I have upsetting thoughts, pictures, or sounds of what happened come into my mind when I do not want them to.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I feel grouchy, angry or mad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I have dreams about what happened or other bad dreams.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I feel like I am back at the time when the bad thing happened, living through it again.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I feel like staying by myself and not being with my friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel alone inside and not close to other people.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I try not to talk about, think about, or have feelings about what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I have trouble feeling happiness or love.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I have trouble feeling sadness or anger.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I feel jumpy or startle easily, like when I hear a loud noise or when something surprises me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I have trouble going to sleep or I wake up often during the night.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I think that some part of what happened is my fault.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>HOW MUCH OF THE TIME DURING THE PAST MONTH</td>
<td>None</td>
<td>Little</td>
<td>Some</td>
<td>Much</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------</td>
<td>------</td>
<td>--------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>15&lt;sub&gt;c3&lt;/sub&gt;</td>
<td>I have trouble remembering important parts of what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16&lt;sub&gt;03&lt;/sub&gt;</td>
<td>I have trouble concentrating or paying attention.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17&lt;sub&gt;c2&lt;/sub&gt;</td>
<td>I try to stay away from people, places, or things that make me remember what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18&lt;sub&gt;b5&lt;/sub&gt;</td>
<td>When something reminds me of what happened, I have strong feelings in my body, like my heart beats fast, my head aches, or my stomach aches.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19&lt;sub&gt;c7&lt;/sub&gt;</td>
<td>I think that I will not live a long life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20&lt;sub&gt;02&lt;/sub&gt;</td>
<td>I have arguments or physical fights.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21&lt;sub&gt;c7&lt;/sub&gt;</td>
<td>I feel pessimistic or negative about my future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22&lt;sub&gt;Af&lt;/sub&gt;</td>
<td>I am afraid that the bad thing will happen again.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
**FOR THE FOLLOWING QUESTIONS, please CHECK [YES] or [NO] to answer HOW YOU FELT during or right after you were burned.**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>15) Were you scared that you would die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16) Were you scared that you would be hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17) Were you hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18) Were you scared that someone else would die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19) Were you scared that someone else would be hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20) Was someone else hurt badly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21) Did someone die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22) Did you feel very scared, like this was one of your most scary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>experiences ever?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23) Did you feel that you could not stop what was happening or that you</td>
<td></td>
<td></td>
</tr>
<tr>
<td>needed someone to help?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24) Did you feel that what you saw was disgusting or gross?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25) Did you run around or act like you were very upset?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26) Did you feel very confused?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27) Did you feel like what was happening did not seem real in some way,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>like it was going on in a movie instead of real life?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
UCLA PTSD INDEX FOR DSM IV (Child Version, Revision 1) © Page 2 of 3

Here is a list of problems people sometimes have after very bad things happen. Please THINK about being burned. Then, READ each problem on the list carefully. CIRCLE ONE of the numbers (0, 1, 2, 3 or 4) that tells how often the problem has happened to you in the past month. Use the Rating Sheet on Page 5 to help you decide how often the problem has happened in the past month.

**PLEASE BE SURE TO ANSWER ALL QUESTIONS**

<table>
<thead>
<tr>
<th>HOW MUCH OF THE TIME DURING THE PAST MONTH</th>
<th>None</th>
<th>Little</th>
<th>Some</th>
<th>Much</th>
<th>Most</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. D4 I watch out for danger or things that I am afraid of.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. B4 When something reminds me of what happened, I get very upset, afraid, or sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. B1 I have upsetting thoughts, pictures, or sounds of what happened come into my mind when I do not want them to.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. D2 I feel grouchy, angry or mad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. B2 I have dreams about what happened or other bad dreams.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. B3 I feel like I am back at the time when the bad thing happened, living through it again.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. C4 I feel like staying by myself and not being with my friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. C5 I feel alone inside and not close to other people.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. C1 I try not to talk about, think about, or have feelings about what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. C6 I have trouble feeling happiness or love.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. C6 I have trouble feeling sadness or anger.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. D5 I feel jumpy or startle easily, like when I hear a loud noise or when something surprises me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. D1 I have trouble going to sleep or I wake up often during the night.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Item</td>
<td>Description</td>
<td>None</td>
<td>Little</td>
<td>Some</td>
<td>Much</td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------</td>
<td>--------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>14AF</td>
<td>I think that some part of what happened is my fault.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15C3</td>
<td>I have trouble remembering important parts of what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16D3</td>
<td>I have trouble concentrating or paying attention.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17C2</td>
<td>I try to stay away from people, places, or things that make me remember what happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18B5</td>
<td>When something reminds me of what happened, I have strong feelings in my body, like my heart beats fast, my head aches, or my stomach aches.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19C7</td>
<td>I think that I will not live a long life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20AF</td>
<td>I am afraid that the bad thing will happen again.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
APPENDIX H. PEDIATRIC QOL INVENTORY, VERSION 4.0:

PARENT AND SELF REPORTS FOR

CHILDREN AND ADOLESCENTS

PedsQL™

Pediatric Quality of Life
Inventory

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by circling:

0 if it is never a problem
1 if it is almost never a problem
2 if it is sometimes a problem
3 if it is often a problem
4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.
**PedsQL 2**

*In the past ONE month, how much of a problem has this been for you...*

<table>
<thead>
<tr>
<th>ABOUT MY HEALTH AND ACTIVITIES (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard for me to walk more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. It is hard for me to run</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. It is hard for me to do sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. It is hard for me to lift something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. It is hard for me to take a bath or shower by myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. It is hard for me to do chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I hurt or ache</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I have low energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABOUT MY FEELINGS (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I feel sad or blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I feel angry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I have trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I worry about what will happen to me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW I GET ALONG WITH OTHERS (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have trouble getting along with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other kids do not want to be my friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Other kids tease me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I cannot do things that other kids my age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. It is hard to keep up when I play with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABOUT SCHOOL (problems with...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard to pay attention in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I forget things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I have trouble keeping up with my schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I miss school because of not feeling well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I miss school to go to the doctor or hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
PedsQL™
Pediatric Quality of Life Inventory
Version 4.0

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

0 if it is never a problem
1 if it is almost never a problem
2 if it is sometimes a problem
3 if it is often a problem
4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.
**PHYSICAL FUNCTIONING (problems with...)**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Walking more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Running</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Participating in sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Lifting something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Taking a bath or shower by him or herself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Doing chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Having hurts or aches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Low energy level</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**EMOTIONAL FUNCTIONING (problems with...)**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Feeling sad or blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Feeling angry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Worrying about what will happen to him or her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**SOCIAL FUNCTIONING (problems with...)**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Getting along with other children</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other kids not wanting to be his or her friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Getting teased by other children</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Not able to do things that other children his or her age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Keeping up when playing with other children</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**SCHOOL FUNCTIONING (problems with...)**

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Paying attention in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Forgetting things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Keeping up with schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Missing school because of not feeling well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Missing school to go to the doctor or hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**PedsQL™**

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for TEENS (ages 13-18)

---

**DIRECTIONS**

On the following page is a list of things that might be a problem for your teen. Please tell us how much of a problem each one has been for your teen during the past ONE month by circling:

0 if it is never a problem  
1 if it is almost never a problem  
2 if it is sometimes a problem  
3 if it is often a problem  
4 if it is almost always a problem

There are no right or wrong answers.  
If you do not understand a question, please ask for help.
In the past **ONE month**, how much of a **problem** has your teen had with ...  

<table>
<thead>
<tr>
<th><strong>PHYSICAL FUNCTIONING (problems with...)</strong></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Walking more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Running</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Participating in sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Lifting something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Taking a bath or shower by him or herself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Doing chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Having hurts or aches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Low energy level</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>EMOTIONAL FUNCTIONING (problems with...)</strong></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Feeling sad or blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Feeling angry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Worrying about what will happen to him or her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>SOCIAL FUNCTIONING (problems with...)</strong></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Getting along with other teens</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other teens not wanting to be his or her friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Getting teased by other teens</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Not able to do things that other teens his or her age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Keeping up with other teens</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>SCHOOL FUNCTIONING (problems with...)</strong></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Paying attention in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Forgetting things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Keeping up with schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Missing school because of not feeling well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Missing school to go to the doctor or hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
PedsQL™
Pediatric Quality of Life
Inventory

Version 4.0

TEEN REPORT (ages 13-18)

DIRECTIONS:
On the following page is a list of things that might be a problem for you.
Please tell us how much of a problem each one has been for you
during the past ONE month by circling:

0 If it is never a problem
1 If it is almost never a problem
2 If it is sometimes a problem
3 If it is often a problem
4 If it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.
**In the past ONE month, how much of a problem has this been for you ...**

<table>
<thead>
<tr>
<th>ABOUT MY HEALTH AND ACTIVITIES (problems with...)</th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard for me to walk more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. It is hard for me to run</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. It is hard for me to do sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. It is hard for me to lift something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. It is hard for me to take a bath or shower by myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. It is hard for me to do chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. I hurt or ache</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. I have low energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABOUT MY FEELINGS (problems with...)</th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. I feel sad or blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. I feel angry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. I have trouble sleeping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. I worry about what will happen to me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW I GET ALONG WITH OTHERS (problems with...)</th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have trouble getting along with other teens</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Other teens do not want to be my friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Other teens tease me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. I cannot do things that other teens my age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. It is hard to keep up with my peers</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>ABOUT SCHOOL (problems with...)</th>
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<th>Almost</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard to pay attention in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. I forget things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. I have trouble keeping up with my schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. I miss school because of not feeling well</td>
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