"YOU'RE PROBABLY THE FIRST PERSON THAT'S ASKED ME":

RETROSPECTIVE NARRATIVES OF ADULTS WHOSE SIBLING EXPERIENCED A

BURN INJURY

by

DANA R. DILLARD

(Under the Direction of Larry Nackerud)

ABSTRACT

The purpose of this study was to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. Innovations in medicine and technology increased the likelihood for individuals to live through and beyond burn traumas that once would have been fatal. The literature consistently supports the acute and lasting influence of a burn injury, both physically and emotionally. When considering children with burn injuries as part of a larger family system, it seems reasonable to expect their burn injury's impact to engulf everyone within their environment. Though research regarding the experience for the family is developing, less is known from the perspective of the uninjured siblings. Sibling relationships—likely the most abiding—have a unique impact on development. Therefore, narrative inquiry was utilized to elucidate the narratives, or stories, of seven adults whose siblings experienced a burn injury in childhood. The three research questions—guided by social constructionism and narrative identity—were: 1) What are the experiences, or stories, of identified adults whose sibling experienced a burn injury? 2) What do the narratives of identified adults whose sibling experienced a burn injury reveal about how their

identities were shaped? 3) What are the implications for program/service development and/or enhancement elucidated by identified adults whose sibling experienced a burn injury? Findings are reported as individual stories using pseudonyms for each participant, along with brief artifact descriptions and images (if provided), a metastory, and five overarching themes that included: 1) separation and alternative caregiving, 2) altered interactions and ambivalent roles, 3) (r)evolving emotional pain, 4) communication concerns, and 5) identity through autobiographical reasoning. The data suggest uninjured siblings have their own unique narratives that have failed to be acknowledged in both research and practice, though all articulated identity clarity and meaning-making in their reflections. Additionally, findings support consideration of many of their experiences as a primary trauma. These results argue the critical need to expand attention—specifically as it relates to inclusion, identity, and resource acquisition—within the burn community. Recommendations for practice and future research are discussed.

INDEX WORDS: Burn Injury, Childhood, Sibling, Narrative Inquiry, Narrative Identity, Autobiographical Reasoning, Meaning-Making, Identity Clarity, Social Work, Qualitative, Psychosocial, Differential Treatment, Caregiving, Separation, Communication

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DEDICATION

This dissertation is dedicated in loving memory to my unconditionally supportive mother

DONNA LYNN ANDERSON

1953-2018

and to my niece and nephew

TANNER and JAKE

I love you more.

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"Patience is the calm acceptance that things can happen in a different order than the one you have in mind." –David G. Allen (2015)

Before I began my doctoral studies, I was advised by a dear friend and mentor, Dr. Nancy Rothenberg, that dissertations were about perseverance, or "stick-to-it-iveness," she would say in jest. After beginning my doctoral program, I heard similar sentiments echoed by senior students as well as one faculty member, Dr. Larry Nackerud. As someone at the end of this long journey, I certainly support the notion that endurance and determination are critical. However, I will admit, when I heard them say that was often the hardest part of the process, I internally sighed some relief. I knew I had persistence. I am my mother's child. And though, this has been a lengthy and demanding journey for me the last five years, at times like trying to tread water during a tsunami, what I think I struggled with the most is patience. Patience, as noted in the quote above, "that things can happen in a different order than the one you have in mind." Things certainly can and did, testing my perseverance in unanticipated ways.

First and foremost, I would like to thank my major professor, Dr. Larry Nackerud. From the doctoral seminar with him that initial semester, I knew Larry was the one who could get me through this process. His intellect and pragmatism are assets I admire. I also appreciate how much he genuinely wants to see students succeed and creates a space that allows for an ease and comfort in approaching him—a quality I hope to emulate in my own work with students. I knew that amidst the chaos I would likely create in my own mind, he would be a calm and practical voice of reason during those times I felt insecure and uncertain. The two simple words, often

employed to close out his emails, "Charge on," provided the necessary reassurance that I was on the right track. I also want to thank Dr. Joon Choi and Dr. Jori Hall—the other valuable members of my committee—for their time, commitment and belief in me from the onset of my coursework in their classes. In addition to my gratitude for serving on my committee, I want to extend my genuine appreciation to all three of you, for your grace and support as colleagues during my mother's illness and subsequent death.

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Admittedly, accomplishing this goal is bittersweet. My mother and father have both passed and will not be able to share in this achievement. My mom told me she knew I would go

back to school one day for this degree. She was always the loudest cheerleader when it came to my education. Well, you were right mom I did. I am at a loss for words knowing you were not able to see this all the way through with me; yet, I am thankful you were with me at the start line. I know you and dad are proud. To my brother, Joshua, and sister-in-law, Jessica, thank you for remaining a steadfast support. To my niece, Tanner, and nephew, Jake—who I absolutely adore—remember I will always believe in you. Always. AND I love you more! I am thankful to some many others along the way, both family and friends—too many to spell out—for their unwavering support and opportunities for respite via dinner, coffee breaks, gym dates, or beach trips. As silly as it may seem, I want to think my fur babies, Grace—who stuck by me for 18 years and began this PhD with me—and Laila—my latest and unexpectedly coveted lap warmer—who will see me to the finish line.

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CHAPTER 1

INTRODUCTION

Innovations in medicine and technology increased the likelihood for individuals to live through and beyond what at one time was considered a fatal experience. In the mid-1970s people with burns covering more than 20% of their body almost always died due to the lack of specialized care facilities, as well as infection and/or other medical complications, such as multiple organ dysfunction, acute respiratory distress, or sepsis (National Institutes of Health [NIH], 2019). However, today individuals experiencing burns over 90% of their body are surviving, though often with lasting damage (NIH, 2019). Burn injury treatment frequently begins with routine debridement, followed by a long and costly hospitalization and/or outpatient treatment, lifelong surgeries (e.g. skin grafts, contracture releases, and reconstruction), and painful physical/occupational therapy, exacerbated by psychosocial challenges (Herndon, 2012; Milner et al., 2015).

According to Van Loey and Van Son, "Burn injuries are among the most extensive and frightening injuries a person can receive" (2003, p. 247). The body endures a physical response to the injury regardless of its etiology—unintentional (e.g. house fire, car accident, scald) or intentional (e.g. abuse, partner violence, self-immolation)—but psychological reactions may also be triggered because of the overall experience, including what was witnessed during the injury (Van Loey & Van Son, 2003). Although decreases in mortality are seemingly positive, these life altering injuries often produce lasting physical and psychosocial consequences (Bakker, Maertens, Van Son, & Van Loey, 2013; Fauerbach et al., 2007; Van Loey & Van Son, 2003;

Wallis et al., 2006) that warrant further discussion for both the person who experienced the burn injury, as well as their family (Bakker et al., 2013; Bakker, Van Loey, Van Son, & der Heijden, 2010; Miller et al., 2013).

Physical scarring and disfigurement are reminders of the incident to the individual who sustained the injury in addition to others they encounter. Consequently, individuals with visible burn scars experience decreased interactions with strangers, as well as friends/family, due to feelings of awkwardness and insecurity, fear of rejection, and exhaustion from managing invasive questions, remarks, and actions (Martin, Byrnes, McGarry, Rea, & Wood, 2017). According to Goffman (1963) and Burke (2007, 2010), family members are not immune to similar consequences and likely develop their own associative identity or "courtesy stigma." The literature is teeming with research exploring the challenges, perspectives, and interventions for individuals who experienced the physical burn trauma (e.g. Baillie, Sellwood, & Wisely, 2014; Dahl, Wickman, & Wengström, 2012; Hunter et al., 2013; Martin, Byrnes, McGarry, Rea, & Wood, 2016; Moi, Vindenes, & Gjengedal, 2014; Palmu, Partonen, Suominen, Vuola, & Isometsä, 2015; Reeve et al., 2011; Renneberg et al., 2014; Rimmer et al., 2013; Thakrar et al., 2015; Tolley & Foroushani, 2014). However, for a more integrative understanding and to assess how to support parts of an entire family system—who are also trying to manage in the wake of the injury—it is essential to expand knowledge and acquire deeper insight regarding the experience of the burn trauma from the perspective of others.

Statement of the Problem

According to the World Health Organization (2019a) burn injuries are a global public health concern that account for approximately 180,000 deaths annually. Reports indicate almost 61,000 children died worldwide in 2008 due to fire or burn injuries (Safe Kids, 2019b). From

1999 to 2013 the death rate from burns and fires decreased by just over 50%; yet, the number of children 19 years of age and younger who died from burn injuries and fires increased 30% from 2012 to 2013 (Safe Kids, 2019a). In the United States, fire departments respond every 24 seconds to fire related calls and in 2017 public fire departments responded to just over 1.3 million fires (National Fire Protection Association, 2019). Additionally, the National Safety Council (2019) posits the odds of an individual succumbing to fire, flame or smoke exposure in 2017 was 1 in 1,474.

The American Burn Association estimates that close to half a million burn injuries received hospital treatment, some in verified "burn centers" (Brigham & Dimick, 2008, p. 250), in 2016; but, this number does not include patients treated in community clinics or primary care offices (American Burn Association [ABA], 2019b). Regrettably, 3,275 deaths occurred that year from fire—or direct flame—and smoke inhalation (ABA, 2019b). At the time of this writing, the American Burn Association's website reports 70 verified burn centers reside in 32 states within the US (2019e). According to their 2019 National Burn Repository Update—a report of data from 2009-2018—children between the ages of one to 15.9 years old comprised 22.5% of the total burn cases (ABA, 2019d). Fire/flame and scalds are the two most commonly reported etiologies, accounting for almost 72% of the reported injuries (ABA, 2019d). For children under the age of 16, scald injuries remain the most prevalent, with fire/flame injuries leading other age groups (ABA, 2019d).

When considering children with burn injuries as part of a larger family system, it seems reasonable to expect the impact of their injury to engulf everyone within the context of their environment. The literature consistently supports the acute and lasting influence of a burn injury, both physically and emotionally (Bakker et al., 2012; Fauerbach & McCann, 2009; Fauerbach et

al., 2007; Miller et al., 2013; Thombs et al., 2008). Furthermore, research on adjustment to a burn injury in families suggests parents/caregivers experience their own emotional response to the incident, which is often complicated by physical absence from their unharmed child(ren) (Bakker et al., 2012; Kilburn & Dheansa, 2014). Consequently, siblings of children with burn injuries are often left in the shadows of the injury, sorting out their own emotional response with little attention afforded to them (Bakker et al., 2013; Lehna, 2008, 2010; Mancuso, 2002; Mancuso, Bishop, Blakeney, Robert, & Gaa, 2003). While there is a paucity exploring the systemic impact on family/caregivers, several recent scholars laid the foundation for this critical work (Bakker et al., 2013; Gullick, Taggart, Johnston, & Ko, 2014; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003; Öster, Hensing, Lojdstrorm, Sjoberg, & Willebrand, 2014; C. Phillips & Rumsey, 2008; Ravindran, Rempel, & Ogilvie, 2013a, 2013b).

Although encouraging, to my knowledge only three studies (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) with specific focus on siblings of children with burn injuries are published in the literature; furthermore, two of the authors (Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) offered explicit implications for future qualitative inquiries to elucidate the emic perspective of the siblings of children with burn injuries not fully advanced by their work. Conroy (2008) took into consideration Mancuso's (2002) findings and recommendations for future research and employed an exclusively qualitative methodology with interestingly convergent and divergent findings. The limited work in this area, specifically the absence of literature highlighting the stories siblings of children with burn injuries, points to a gap in knowledge, with substantive, theoretical, and social work practice implications.

Purpose of Study and Research Questions

The purpose of this study was to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. To gain a focused perspective of siblings of children with burn injuries it was central to inquire directly at the source of knowledge. Through their lived experience, siblings of children with burn injuries are the authorities of their narrative. The stories shared are recognized as their truth or reality that informed implications within the context of their family and world, based on meanings made from the experience at the study's point in time—not the "real thing" but participants' representation of them (Riessman, 1993, 2008).

Clandinin (2013) recommends researchers embrace moving from an idea of research questions that suggests precision or specificity in outcomes and instead consider it a puzzle where a sense of search is understood. However, since research questions are generally the expectation—especially for dissertations—narrative inquiry typically poses questions seeking to describe stories/experiences of people's lives and/or how identity was constructed/renegotiated following an event/circumstance (e.g. Hunter et al., 2013; Kempson & Murdock, 2010; McKelvey, n.d.) (Riessman, 1993, 2008; Sandelowski, 1991). Therefore, the current study was guided by these central questions:

1. What are the experiences, or stories, of identified adults whose sibling experienced a burn injury?

2. What do the narratives of identified adults whose sibling experienced a burn injury reveal about how their identities were shaped?

3. What are the implications for program/service development and/or enhancement elucidated by identified adults whose sibling experienced a burn injury?

Theoretical Frameworks

This study was concerned with elucidating the stories of adults whose sibling experienced a burn injury to appreciate how their identity was shaped by the incident, as well as solicit implications for program/service development and/or enhancement. As such, the two overarching frameworks that guided this study were social constructionism and narrative identity. Social constructionism seeks to understand the word in which individuals live (Lincoln & Guba, 2000; Schwandt, 2000) with the assumption that the world must be interpreted rather than observed (Haverkamp & Young, 2007; Lincoln & Guba, 2000; Schwandt, 2000). Knowledge of the self and world originates from human relationships (Gergen & Gergen, 2008) through the important tenet of language, and, as such, the collective perspective of knowledge refutes the idea of one truth and instead advances numerous varied, though equally valid realities (Gergen & Gergen, 2008; Guba & Lincoln, 1994; Schwandt, 2000). Therefore, social constructionism assumes a pragmatic approach to knowledge, positing "It is not whether an account is true from a god's eye view that matters, but rather, the implications for cultural life that follow from taking any truth claim seriously" (Gergen & Gergen, 2008, p. 818).

According to McAdams, Josselson, and Lieblich, "We are all storytellers, and we are the stories we tell" (2006, p. 3). McAdams (2018) suggests that if identity was a thing, we could see it would look like a story since narrative is the natural way we think and express ourselves (Bruner, 1990); yet the idea of identity as a life story—or what has evolved to be considered narrative identity—is a unique kind of story because it elucidates how we came to be who we are and are becoming (McAdams, 2018). Narrative identity assumes that identities evolve over time and are shaped by the stories individuals create and tell about their lives for themselves and others (McAdams et al., 2006). Thus, it beholds inherent assumptions around development and

integration. Our stories become more complex and detailed as we evolve from childhood through adolescence and into young adulthood (Fivush & Haden, 2003). Habermas and Bluck (2000) argue that by adolescence our lives are considered interwoven narratives of the self. Accordingly, this aligns with Erik Erikson's (1963) period of identity development where the task focuses on a stable sense of identity. There are primary two approaches to exploring identity development derived from Erikson (1968)—identity status and narrative (McLean & Pasupathi, 2012). Identity status is concerned with the advancement of identity exploration to the level of commitment, or identity achievement, by managing crisis; whereas, narrative approaches (i.e. narrative identity) place emphasis on life span development and psychobiography (McLean & Pasupathi, 2012; McLean & Pratt, 2006; J. A. Singer, 2004). The later was the approach employed for this study (McAdams & McLean, 2013). Lastly, narrative identity assumes that the construction of a life narrative is a reflexive exercise that facilitates the ability for individuals to extract meaning when their stories are retold (J. A. Singer, 2004).

Consequently, social constructionism and narrative identity align well with social work research and practice as a field engaged in considering individuals/groups and their relationships to various circumstances and backgrounds across social, cultural, and historical contexts and how this intersects with their ability to look reflexively at their life, or narrative (J. Phillips, MacGiollaRi, & Callaghan, 2012; Witkin, 2012). As outlined in the National Association of Social Workers (NASW) code of ethics, "A historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society" (NASW, 2017). Social work recognizes self-determination as an ethical standard (NASW, 2017) and challenges the researcher or practitioner to meet individuals where they are, which arguably supports social constructionism refuting the notion of a single truth, objectivity, or expert.

Instead, one of social work's core values, *Importance of Human Relationships*, relates "Social workers engage people as partners in the helping process" (NASW, 2017). When social work scholar Dennis Saleebey was interviewed about how he thought social constructionism could inform the field of social work, he stated, "You have to suspend your own disbelief...*and* [emphasis in original] belief, and you have to create an environment where people understand that *you* [emphasis in original] understand that there may be many truths about a situation" (J. C. Hall, 2014, p. 9). Social constructionism and narrative identity promote that milieu.

Brief Overview of Methodology

Narrative inquiry (Riessman, 1993, 2008) was utilized to elucidate the narratives of seven adults whose siblings experienced a burn injury. Although a purposeful criterion sampling method (Onwuegbuzie & Leech, 2007; Patton, 2015) was initially employed, due to challenges accessing the potential participants, it became necessary to also engage sequential and emergence-driven strategies, such as convenience or snowball sampling, because of their recognized strength in accessing populations that are unknown (Noy, 2008; Onwuegbuzie & Leech, 2007; Patton, 2015). Once participants were located, their interest was determined, and the criteria was met, interviews occurred either in person or with the technology assisted technique of video conferencing (i.e. FaceTime) between September 2017 and November 2018. Participants were also asked to provide an artifact at the time of the interview they felt represented their relationship with their sibling either before, during or after the burn injury. The interviews were recorded digitally on three different devices and photographic images captured of the artifacts. Interviews were subsequently professionally transcribed. However, I also thoroughly reviewed and sanitized the transcripts utilizing Express Scribe Transcription Software (Version 7.03). Next, the files were moved into the qualitative data analysis software (QDAS)

ATLAS.ti (Version 8.3.1). Texts were read multiple times and van Manen's (1990) selective or highlight approach was used to capture phrases/quotes that seemed essential or informative regarding the experience of growing up with a sibling who experienced a burn injury. Through an iterative approach to analysis themes were identified across participant stories. I employed the use of an audit trail and memoing during analysis that facilitated data quality. Furthermore, each participant was sent their individual story, along with a brief explanation of each of the five themes and supporting quotes, to engage the process of member checking and safeguard the accuracy of my interpretations. A colleague in the burn community also reviewed my interpretations and findings. Data was represented in the form of detailed stories for all participants—along with brief artifact descriptions and images (if provided)—a metastory, and overarching themes. Chapter 3 will provide a more comprehensive explanation of the methodology.

Significance of Study

Literature regarding burn injury trauma has primarily been limited to the experience and impact of the person who sustained the physical burn injury. Although research exploring the systemic impact of a burn injury on the family/caregivers has expanded, there remains room for significant growth and development. Particularly underrepresented in the literature are studies detailing the unique experience of growing up with a sibling who experienced a burn injury. The three studies (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) delineated above that did survey this topic are dated. The most recent studies were conducted over a decade ago and the earliest inquiry was made almost two decades ago. Furthermore, two of the studies (Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) employed both qualitative and quantitative measures, as well as parent proxies, and outlined specific

recommendations for future qualitative inquiries to reveal the unique perspective of siblings of children with burn injuries. Findings from one of the most recent studies (Conroy, 2008), which did solely engage qualitative interviews with children between the ages of 8 and 18 years old, varied in a number of areas from previous research.

Consequently, much remains to be understood about the experience of siblings of children with burn injuries, positioning this study to fill a gap in substantive and theoretical knowledge, while concurrently building upon the foundation of earlier scholars to inform social work practice. Adults were utilized to provide their perspective on having a sibling who experienced a burn injury in childhood with the intent offering a more mature and developed perspective on themselves and the experience (Habermas & Bluck, 2000; Pasupathi & Mansour, 2006). This study was the first to engage a retrospective approach to understanding the experience of siblings of children with burn injuries. Their reflection encouraged a more dynamic and integrative perspective that enhanced our understanding of how their identity was impacted. Lastly, the siblings who participated in this study and shared their story, many for the first time, articulated feeling empowered by retelling their experience and encouraged that through their participation they were likely helping others.

Definition of Terms

The section presents a number of terms and defines their use as presented in this study. While beyond the scope of this paper, it is worth noting the ongoing debate around person-first and person-centered language (Kapitan, 2017; Mackelprang, 2013). Person-first language (e.g. sibling with a burn injury) developed among disability advocacy groups in the 1980s and was widely accepted under the premise individuals are not defined by their differences, but rather they are characteristics they live with (Kapitan, 2017; Mackelprang, 2013). However, there has

been a shift from person-first language to language that emphasizes identity (e.g. uninjured

sibling) (Mackelprang, 2013). Yet, even still, many argue that it is presumptuous to define

someone without taking the individual's own thoughts into consideration first (i.e. person-

centered) and allow them to be the experts on how they choose to be defined (Kapitan, 2017).

Thus, I recognize the inherent challenges and presumptions in discourse, and it is in the spirit of

brevity and readability—not paternalism or disrespect—I chose to delineate the terms

injured/uninjured sibling below.

Burn camp: generally considered a recreational program provided for children who experienced

a burn injury; however, of note, there are a number of camps around North America with varied

frameworks and inclusion criteria (International Association of Burn Camps, 2019a).

Burn community: those individuals/families/friends impacted by burn injuries, as well as burn

care medical/allied health professionals, organizations/agencies providing services to those

impacted by burns, and members of the fire service.

Cosmetic change: altered appearance or visible differences as a result of a burn injury, which

may include skin grafts, marks, wounds, hypertrophic scarring, or the loss of body parts (e.g.

arm, leg, nose, eye, ear, fingers).

Injured sibling: a sibling who experienced a burn injury.

Parent: it is recognized individuals caring for children may not always be their biological parent;

however, the term will be used in this paper with the understanding that individuals referred to as

such are conceptualized as those who are providing and caring for children at that capacity.

Uninjured sibling: a sibling who did not experience a burn injury.

CHAPTER 2

LITERATURE REVIEW

Introduction

The first chapter provided a brief introduction, statement of the problem, purpose of study, presentation of research questions, theoretical frameworks, study significance and defined terms presented in the study. Specifically, the aim of the study was to contribute to the limited knowledge regarding the experience of uninjured siblings by elucidating their accounts, or narratives, while paying attention to how their identity was shaped. Moreover, through these detailed accounts implications for program service/development and/or enhancement was gained. The subsequent chapters will address literature pertinent to the subject, as well as detail the research methodology and present the findings, and finally culminate in the closing chapter that features conclusions and implications of the study.

Chapter 2 focuses on a review of the literature that was relevant to informing this study. According to Boote and Beile (2007), "To advance our collective understanding, a researcher or scholar needs to understand what has been done before, the strengths and weaknesses of existing studies, and what they might mean" (p. 3). As such, it is critical to ascertain germane knowledge in order to promote research that has both meaning and utility (Boote & Beile, 2007). Maxwell (2007) argues for literature reviews that are "focused on relevance rather and comprehensiveness" (p. 31) and conceptualizes them as "an essential component of research rather than a foundation" (p. 31). Focusing on the relevance of materials provides critical implications for how research is designed or carried out, rather than just providing knowledge on

the topic (Maxwell, 2007). Furthermore, Rudestam and Newton (2015) posit, "A good literature review needs to be selective, and it is taken for granted that the majority of source material you have read will not make it directly into the literature review" (p. 73-74). The following literature review commences with a brief overview of burn injuries and their treatment, followed by a discussion about the location of burns in the literature, then details the burn community, trailed by a review of literature researching the family and sibling perspectives of a burn injury, and concludes with a brief discussion about interventions being utilized within the burn community.

Burn Injury Overview

Burn injuries have been treated for over 3500 years with the first direct evidence originating from the discovery of Neanderthal man's cave paintings (Barrow & Herndon, 2007). Burn trauma can be caused via thermal, radiation, chemical or electrical contact (Johns Hopkins Medicine, 2019) and result in either first, second, third, or fourth degree injuries (University of Rochester Medical Center, 2019). Thermal injuries can happen in a variety of ways (e.g. scalding liquids, hot metals, steam, or flames) and are produced when the temperature of the skin and its surrounding tissues are raised, which results in either destroying or charring skin cells (Johns Hopkins Medicine, 2019). Radiation wounds result from extended exposure to the sun's ultraviolet rays, as well as prolonged exposure to radiation therapy frequently used in the treatment of cancerous cells (Cancer Treatment Centers of America, 2019; Johns Hopkins Medicine, 2019). Contact with chemical agents, such as household/industrial cleaners and other strong acids and solvents, yield chemical burns (Johns Hopkins Medicine, 2019). Finally, electrical burn injuries occur via sources of electricity, including lightning (Johns Hopkins Medicine, 2019).

Burn etiology does not dictate the classification of a burn; rather, it is determined by the depth and severity of the injury (University of Rochester Medical Center, 2019). First-degree, or superficial, burns typically impact the outer layer of the epidermis and result in red, dry, painful wounds (e.g. sunburn) that are tender to the touch, but do not produce sustained tissue damage (University of Rochester Medical Center, 2019). Second-degree, also known as partial thickness, burns result in blistered red skin that may be swollen and painful, impacting both the epidermis and dermis layers of the skin (University of Rochester Medical Center, 2019). If damage is severe enough to destroy both the epidermis and dermis, penetrating the subcutaneous tissue, and appears white or blackened and charred, it is classified as a full thickness, or third-degree, injury. Finally, fourth-degree burns devastate both layers of the skin and its underlying and deeper tissue, engaging both muscle and bone, resulting in areas that are void of feeling due to the elimination of nerve endings (University of Rochester Medical Center, 2019).

There are several methods accessible to determine the total body surface area (TBSA), referred to as a percentage, of injury that include Rule of Nines, Lund and Browder Chart—argued as a more precise method, particularly with children—and Palmer Surface (Schaefer & Szymanski, 2019). Burns are further classified as minor if they are 15% or less TBSA, moderate if the TBSA is between 15% and 25%, and major/severe if the TBSA is greater than 25% (Hettiaratchy & Papini, 2004; Lin et al., 2019). However, burns less than 20% TBSA in both older adults and children may still be considered severe (Gauglitz & Williams, 2019). The American Burn Association (2019a) outlines criteria for burn injuries that should be referred to a specialized burn center for treatment that includes: (a) partial thickness burns larger than 10% TBSA; (b) injury to the face, hands, feet, genitalia, perineum, or major joints; (c) any age group with third-degree wounds; (d) electrical burns; (e) chemical burns; (f) inhalation injury; (g)

injuries in individuals with pre-existing medical conditions that may complicate recovery or impact mortality; (h) individuals with concomitant trauma—only if the burn injury poses the greatest risk of death or morbidity; (i) children in hospitals without trained personnel or proper equipment to manage their burn injury care; and (j) individuals who require special interventions related to their social, emotional or rehabilitative needs.

Burn injuries involve a variety of physical conditions and/or treatments, many of which have advanced over the years (Rowan et al., 2015; Van Loey & Van Son, 2003), that will be discussed briefly next. The skin's primary role is to function in a protective capacity as a barrier to environmental factors; as such, the loss of its integrity, especially in large portions, increase the chances of major illness/disability or mortality (A. J. Singer & Clark, 1999). Therefore, physical burn traumas begin with stabilization that includes fluid resuscitation, respiratory support, cardiovascular stabilization, pain control and the general management—particularly infection control—of the wounds (Gauglitz & Williams, 2019; Rowan et al., 2015). Silvadene is a common topical antimicrobial medication indicated for individuals who sustain second and third degree burn injuries to prevent/treat sepsis (Garg et al., 2019; RxList, 2019). Patients with major burn injuries are at a heightened risk for impaired organs caused by numerous etiologies, as well as an increased risk for infection (Gauglitz & Williams, 2019; Rowan et al., 2015). Another important, but complex, area of consideration in the management of burn wounds is nutrition (Gauglitz & Williams, 2019). This is due to the potential of burn wounds to result in tireless and sustained hypermetabolic states—often exceeding twice the normal metabolic rates—that can lead to muscle wasting and cachexia, which further exacerbates wound healing, organ failure, and increases vulnerability to infection (Clark, Imran, Madni, & Wolf, 2017).

The standard of care in wound management has called for early excision and grafting (Rowan et al., 2015). Due to sustained considerations of infection, excising the dead skin tissue—or eschar—and early coverage of wounds is urgent (Rowan et al., 2015). Debridement is a painful procedure developed in 1925 by Dr. Edward Clark Davidson at Henry Ford Hospital, which originally involved manually opening up and scrapping off blisters (Ravage, 2004). Today it can be done in a number of ways including mechanically, chemically, surgically, or a combination of the three (Ravage, 2004). The goal of the debriding process is to remove all dead tissue in order to expose healthy tissue, which will either heal on its own or be used in skin grafts (Ravage, 2004). The procedure is endured repetitively, often daily, to help promote healing with ongoing debates within the context of infection control about the use of tanks or tubs versus performing it at the bedside (Ravage, 2004). Even the use of pain medications cannot disguise the agony of the procedure, which an individual who experienced burns over 20 years described as follows, "It felt like a wire brush raking against my raw flesh. I would scream and cry and beg them to stop. I can still hear my own screams today" (Ravage, 2004, p. 162). Numerous burn centers currently employ what is known as hydrotherapy, which is a procedure that involves hosing patients off from head to toe—though still subjecting patients to pain and potential infection—with sustained arguments around the procedure itself, as well as the use of more aggressive pain control in attempts to minimize the painful debriding procedure (Ravage, 2004).

In terms of grafting, autographs—a skin graft taken directly from the uninjured skin of the same patient—are the standard of care for full-thickness (i.e. third and fourth degree) injuries (Rowan et al., 2015), though these can be problematic for patients with a larger TBSA of burns that thus offer less area from which to harvest healthy tissue (Ravage, 2004). Additionally, these grafts may be rejected, presenting their own wound management burden, and are also extremely

painful (Akan et al., 2003). Alternatively, other methods of grafting skin include: allografts—tissue from either a living or deceased donor; xenografts—tissue taken from a different species; and skin substitutes or dermal analogs—often pharmaceutically manufactured options (Rowan et al., 2015). The size and depth of the burn injury have implications on wound healing, and, as such, scarring to the skin (Ravage, 2004; Rowan et al., 2015; Van Loey & Van Son, 2003). One outcome is tissue development that is overly grown and results in thickened, red, and hardened scars, also known as hypertrophic scars (Ravage, 2004; Van Loey & Van Son, 2003). An alternate outcome is thin and fragile tissue, which increases the duration of healing since skin is likely to breakdown and tear more easily, resulting in chronic wounds and an increased risk for skin cancer (Ravage, 2004). Furthermore, malformations to fingernails are common when burn injuries are sustained to the hand and produce altered appearances often due to soft tissue contracture near the cuticle (Donelan & Garcia, 2006). As a result, the nailbed peels away producing either subtle changes in shape and location of the cuticle or the complete absence of nail growth (Donelan & Garcia, 2006).

Hypertrophic scars can be problematic beyond their appearance and produce tissue that will not flatten, often behaving as tough knots, which can also become inflamed, itchy, painful, and impairing due to the loss of functionality and contractures (Ravage, 2004; Van Loey & Van Son, 2003). One commonly employed method to assist in the management of hypertrophic scarring is the use of pressure garment therapy (PGT) (Anzarut, Praby, Rowe, Tredget, & Oldson, 2006; Atiyeh, El Katib, & Dibo, 2013; DeBruler et al., 2018), though the efficacy of PGT remains an ongoing debate in the literature (Anzarut et al., 2006; DeBruler et al., 2018). The garments themselves are custom made pieces of elasticized material with pressure that is determined by the number of fabric layers, as well as fabric grain direction in relationship to an

individual's own body dimensions and injuries (Leung, Yuen, Ng, & Shi, 2010). Additionally, masks made of either elastic or transparent materials are also utilized for individuals who sustained injury to the face (Rogers et al., 2003).

The pressure garments themselves present another set of challenges to the patients' recovery. The garments are typically worn almost 24 hours a day (Ripper, Renneberg, Landmann, Weigel, & Germann, 2009) anywhere from 4 to 6 months up to 2 years, with the most common recommended use of 1 year (DeBruler et al., 2018; Ripper et al., 2009). Noncompliance with PGT is common with patients describing garments to be hot and itchy with limited functional mobility (DeBruler et al., 2018; Ripper et al., 2009) and also reporting they elicit negative reactions from the public and at times their family (Ripper et al., 2009). PGT compliance is supported in the literature as an issue with adults (Ripper et al., 2009) and children (N. Andrews et al., 2018); though, in the pediatric population it is often negotiated within the context of parent and child relations when considering the necessity to meet clinical demands while also grappling with the practical and emotional factors (N. Andrews et al., 2018).

Due to the advances in managing burn trauma and the decreased mortality noted earlier (NIH 2019), individuals are now surviving with burns that require more complex rehabilitation needs in addition to the wound care, nutrition, and scar management noted above (Richard et al., 2009) that is often a lasting process (Gauffin, Öster, Sjöberg, Gerdin, & Ekselius, 2016; Gauglitz & Williams, 2019; Renneberg et al., 2014). Rehabilitation is considered through the lens of multiple team members who represent different areas of specialty that includes physical recovery and psychosocial recovery (Richard et al., 2009). Burn therapists are traditionally thought of as occupational and physical therapists, or professionals providing care within the physical context (Richard, 2014; Richard et al., 2009). Both occupational and physical therapy are routine,

frequently painful, components in an injured patient's recovery (Ravage, 2004) with often

overlapping goals discussed within the burn literature (Biggs, Linde, Banaszewski, & Heinrich,

1998; Richard et al., 2009). Occupational therapists are typically involved in smaller muscle

groups and manipulative function, frequently referred to as activities of daily living (Ravage,

2004). Physical therapists, on the other hand, engage the larger muscle groups to help with

ambulation and revitalizing strength in muscles often damaged excessively by both the burn

injury itself, as well as atrophy from decreased usage (Ravage, 2004). However, both are

important within the context of scar tissue management, potential scar shrinkage, and contracture

(Ravage, 2004).

Psychosocial recovery is also an ongoing rehabilitative process (Dahl et al., 2012;

Gauffin et al., 2016; Renneberg et al., 2014; Van Loey & Van Son, 2003; Wallis et al., 2006),

with findings that suggest psychosocial care needs are higher than physical needs in patients after

discharge (Liang, Wang, Yao, Pan, & Wang, 2012). During acute hospitalization patients are

more likely to have access to psychosocial professionals (e.g. social worker, psychologist,

psychiatrist) (Blakeney, Rosenberg, Rosenberg, & Faber, 2008); yet, the importance for

sustained access to post discharge, or aftercare, psychosocial resources remains equally as

important and an evolving area within the burn community (Acton, Badger, & O'Leary, 2017;

Broerse, Zweekhorst, van Rensen, & de Haan, 2010; Holavanahalli, Badger, & Acton, 2017;

Rivas et al., 2018). Discharge plans from the acute setting are routinely considered from the

moment a patient is admitted with trends now focusing on a phase referred to as reintegration,

which occurs after discharge when patients—and families—are adapting to possible changes

with the injured individual's body, as well as negotiating social interactions, following the injury

(Blakeney et al., 2008). The following section will provide consideration for the location of burn injuries in the body of literature.

Unpacking Burns—Location of Burn Injuries in the Literature

It is currently unclear where a burn injury fits within the larger context of research. Beginning with chronic conditions—such as illness and disease—there is a lack of conceptual clarity with the two constructs often employed interchangeably, although they vary considerably (Goodman, Posner, Huang, Parekh, & Koh, 2013). In the editorial section for the introductory issue of *Chronic Illness* journal, chronic illnesses were defined as "prolonged, do not resolve spontaneously, and are rarely completely cured" (Dowrick, Dixon-Woods, Holman, & Weinman, 2005, p. 1). Specifically, they advised the journal would be concerned with two primary issues: duration (e.g. long-term, long-lasting, intractable, and chronic); and entities (e.g. disease, condition, medical condition, and illness) (Dowrick et al., 2005). The journal acknowledged the politically charged context within chronic illness research and welcomed both qualitative and quantitative research in the hopes that findings would begin to elucidate what it means to be an individual who is living with a chronic illness, as well as how it impacts their sense of self and worldview (Dowrick et al., 2005). A search of the term "burn" in the journal from 2005 through present resulted in 19 articles. However, the contexts of the words included the following usage: proper noun (n=7); burn out (n=7); burning sensation/pain (n=4); and a comorbid participant who experienced a burn injury (n=1).

Within the context of chronic disease literature, clarity also remains obscured with degrees of variation in how the term is employed, as well as the duration the disease must be present for it to be considered chronic (Bernell & Howard, 2016). According to the Centers for Disease Control (CDC), "chronic diseases are broadly defined as conditions that last 1 year or

more and require ongoing medical attention or limit activities of daily living or both" (2019). The CDC (2019) highlights heart disease, cancer, and diabetes as primary examples, and the World Health Organization (WHO) includes those and adds chronic obstructive pulmonary disease (2019b). Interestingly, the WHO (2019e) refers to chronic diseases as noncommunicable diseases and posits they "tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours [*sic*] factors."

Shifting into the area of disability, arguments for construct agreement are also urgently invited (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006). Specifically, Leonardi et al. (2006) call for a definition that: (a) does not segregate based on disability (e.g. hearing impaired) or chronic illness; (b) allows description across functional areas; (c) permits comparison of severity across types; (d) extends flexibility across contexts (research versus practical); promotes comprehensiveness; (e) acknowledges the impact of one's environment on their disability; and (f) omits requirements regarding causality. Under the Americans with Disability Act (ADA) "disability" is context specific, relating to a legal definition instead of a medical definition (American Disability Act National Network, 2019). The WHO (2019c, 2019d) posits disability is an umbrella term that covers "impairments, activity limitations, and participation restrictions" and is not specifically a health-related problem. Rather, it is a more complicated and diverse experience that involves the interactions of one's body in relationship to society (World Health Organization, 2019c, 2019d).

Theoretically burn injuries could fit into one or both categories of chronic conditions (i.e. illness/disease) and disability, due to the potentially long term physical and psychosocial recovery, as well as yielding damages that impact body function or structure and restrict activities and engagement, thereby concurrently influencing their personal and societal

interactions. However, to my knowledge burns have not been included specifically within the context of either of these classifications. The meta-analysis (Sharpe & Rossiter, 2002) and literature reviews (Hartling et al., 2014; Knecht, Hellmers, & Metzing, 2015) included the following illness, "chronic health problem," and/or disability: HIV/AIDS, cancer, cystic fibrosis, cerebral palsy, rheumatic disease, inflammatory bowel disease, congenitally impaired, infantile hydrocephalus, end-stage renal disease, diabetes, physically handicapped, hearing-impaired, myelomeningocele, thalassemic, epilepsy, sickle cell anemia, leukemia, liver transplant, spina bifida, nephrotic syndrome, autism, neonates, ADHD, meningitis, learning disabilities, developmental disabilities, down syndrome, brain injury, cardiac anomaly, Chron's disease, kidney failure, abdominal pain, asthma, gastrointestinal disorders, and hematologic disease.

Complex care is another growing area of consideration in the literature that is also vaguely conceptualized with little consensus on the concept, which creates space for unclear understanding (Brenner et al., 2018; Cohen et al., 2011). Through a systematic concept analysis of multidisciplinary language Brenner et al. (2018) posited the following explanation of children's complex care needs (CCN):

> [They] refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures. (p. 1641)

As such, inherent in CCN's description is the inability of a single profession or discipline to provide quality care and meet the needs of the population (Brenner et al., 2018), as well as a lack of specificity regarding specific medical conditions or diagnoses. Though the systematic concept analysis focused on a pediatric population, CCN are discussed with populations of all ages (e.g.

Bayliss, Ellis, Powers, Gozansky, & Zeng, 2019; Lindsay & Hoffman, 2015). Furthermore, *The National Center for Complex Health and Social Needs* (2019) was launched in 2016 "to improve outcomes for individuals with complex medical, behavioral, and social needs." As such, a burn injury may fall into this category, though to date no specific study was located that referred explicitly to burns within the context of the CCN cataloging.

Trauma is another complex and prolific concept in the literature. Changes to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed. DSM-5; American Psychiatric Association [APA], 2013) resulted in a revised definition, which removed the subjective response and enabled reactions to include something other than "intense fear, helplessness, or horror" (4th ed. DSM-IV-TR; APA, 2000 p. 467), including the absence of a pronounced emotional response (Jones & Cureton, 2014). However, Brewin, Lanius, Novac, Schnyder, and Galea (2009) argued the first criterion, which outlines four triggers of trauma, should be abolished and left for the individual to define what they consider a traumatic event, since what one person considers traumatic another person may not. Hall and Hall (2013) acknowledged "medical trauma" is not a familiar term among health professionals and reasoned trauma experienced as a result of medical procedures, illness, and hospital stays can have enduring results that create a different experience from other traumas.

Burn injuries are well positioned to fall within the parameters of a trauma based on the DSM-5 for both those who experienced the injury directly, as well as others—specifically uninjured siblings in this study—who witnessed the event as it happened to someone else, or, learned that a traumatic event occurred to a family member or friend (APA, 2013; Jones & Cureton, 2014). A cursory search of the two journals (*Burns* and *Journal of Burn Care and Research*)—discussed in greater detail in the next section—with verified impact scores yielded

the following inventory of articles based on these search words, suggesting the presence of the trauma construct within burn specific literature: "trauma," *Burns*—4262 and *Journal of Burn Care and Research*—2284; "psychological AND trauma," *Burns*—647 and *Journal of Burn Care and* Research—498; and "psychological trauma," *Burns*—51 and *Journal of Burn Care and Research*—37.

When confronting the location of burn injuries in the body of research several questions are raised: Are these injuries associated with the constructs of chronic conditions (i.e. illness/disease), disability, CCN, or trauma? Could they be associated with all, some, or none of the above? Although burn injuries can result in long-term health problems requiring ongoing medical care (Gauffin et al., 2016; Gauglitz & Williams, 2019; Renneberg et al., 2014) lending credence to a chronic condition, not all injuries result in a loss of function, or disability. Yet, they do engage multiple disciplines congruent with CCN (Greiser, Murray, Lorello, Foster, & Caruso, 2018; Richard et al., 2009). Furthermore, trauma appears a grounded concept within the burn literature. One question appears to beget another while grappling with burns location in the literature. Regardless, the overall assumption subsequent to a burn injury is a disruption in perceived quality of life that for some endures (Gauffin et al., 2016; Gauglitz & Williams, 2019; Renneberg et al., 2014; Wallis et al., 2006).

The previous discussion suggesting conceptual ambiguity and inconsistent positioning of information in the literature is not to advocate the need for burn injuries as a positivistic classification of chronic condition (i.e. illness/disease), disability, CCN, or trauma. Instead it proposed to acknowledge the tensions and ambiguity around its location, recognizing that these injuries span the scope of the various constructs. Yet, it is critical to promote this awareness, perhaps at times perceived in conflict, and consider the interpretations of a burn injury, and

accordingly, implications within the context of stigma and identity from multiple perspectives—not solely the person who sustained the physical phenomena (T. Andrews, 2012; Lincoln & Guba, 2000; Witkin, 2012). The following section will address the burn community—or those individuals/families/friends impacted by burn injuries, as well as burn care medical/allied health professionals, organizations/agencies providing services to those impacted by burns, and members of the fire service—in greater detail, including how it fits within the context of acute injury, as well as aftercare/reintegration.

The Burn Community

Subsequent to increased survival, a number of organizations developed to establish resources for individuals impacted by burn injuries. The American Burn Association (2019f) was established over 50 years ago and at present has over 2,000 members in United States, Canada, Europe, Asia and Latin America. The organization has a multidisciplinary membership—physicians, nurses, researchers, social workers, physical and occupational therapists, members of the fire service and burn centers—that is "dedicated to improving the lives of everyone affected by a burn injury" (American Burn Association, 2019f). The Phoenix Society for Burn Survivors (2019a), founded in 1977, is one of the first burn support organizations in the United States and the leading national organization with the following vision, "Uniting the voice of the burn community across the globe to profoundly advance lifelong healing, optimal recovery, and burn prevention." One of their largest programs is a weeklong annual conference (i.e. World Burn Congress) for the burn community that facilitates opportunities for individuals to connect with others impacted by a burn injury—for many their first chance—via speakers, breakout sessions, and social events (Phoenix Society for Burn Survivors, 2019b).

Several years later in 1986, the Federation of Burn Foundations (2019) was created to:

[E]mpower burn organizations to better serve their communities through: communication
and information exchange among member organizations; promotion and public policy
beneficial to burn prevention, care research and/or burn survivors; liaison with other
organizations with similar or compatible purposes; enhancing the capabilities of members
by promoting and assisting in the development of best practices for burn foundations.

According to their 2016-2017 membership directory (Federation of Burn Foundations, 2017)
there are 29 member organizations/foundations, located in 13 states, a district, and four Canadian
provinces. In 2001, the International Association of Burn Camps (2019b) was founded to support
programs serving the burn community via burn camps. Furthermore, the International
Association of Fire Fighters Foundation (2019) supports both the American Burn Association, as
well as the Phoenix Society for Burn Survivors, and also hosts an annual burn camp.

Additionally, five journals are exclusively dedicated to burn research: *Burns* (2019), a
publication of the International Society for Burn Injuries; *Journal of Burn Care and Research*
(2019c), a publication of the American Burn Association; *Burns and Trauma* (2019), sponsored
by the First Affiliated Hospital of Army Medical University; *International Journal of Burns and
Trauma* (2019)*, published by e-Century Publishing; and *Scars, Burns, and Healing* (2019),
published by Sage in association with the Katie Piper Foundation (2019) . The first two journals
are listed in the order of their 2018 journal impact score (2.134 and 1.923, respectively)
(Clarivate Analytics, 2018). The remaining three are listed in alphabetical order in the absence of
being able to locate their journal impact scores. The only journal not listed as open access is the
Journal of Burn Care and Research (2019), which is only available to active American Burn
Association members, though they offer a few articles to non-members.

Symbol of Identity

The name of the national organization—the Phoenix Society for Burn Survivors—implicitly alludes to the culture in the burn community. According to the Oxford Dictionary (2019), phoenix—which is also used pictorially in their logo—is defined as a unique bird from classical mythology "that lived for five or six centuries in the Arabian desert, after this time burning itself on a funeral pyre and rising from the ashes with renewed youth to live through another cycle," as well as, "[a] person or thing regarded as uniquely remarkable in some respect." Furthermore, use of the term *burn survivor* is ubiquitous in the burn community, including burn-focused publications and peer-reviewed journals, though it remains ambiguous how the construct is defined (i.e. Who or what is a *burn survivor*?) (Dillard, 2015).

According to the Phoenix Society for Burn Survivors' (2019c) website, "[W]e work with burn survivors, their loved ones, firefighters, and medical teams across the country to care for the whole person after a burn injury." This seems to imply family (i.e. "their loved ones") are not included in the construct of *burn survivor*. However, according to the Executive Director of a burn foundation, who himself sustained burn injuries over 40 years ago, "Burn survivors are anyone impacted by a burn, such as the mother, father, sister, brother, husband, wife, etc." (D. Gardin, personal communication August 8, 2016), and the organization he oversees works within this framework when providing programs/services. Though defining *burn survivor* is beyond the scope of this study and warrants further consideration (Dillard, 2015), the language facilitates some insight, albeit unclear, with implications on cultural aspects of the burn community and more specifically uninjured siblings in this study—particularly as it relates to inclusion, identity, and resource acquisition.

"Burn-injured by Association?"

While the boundaries of *burn survivor* remain unclear, Goffman (1963) and Burke (2007, 2010) offer valuable ideas positioned within the framework of stigma and family/individual identity. Erving Goffman (1963) explored the way individuals with "spoiled identities" manage their persona to conceal their stigma, which he defined as, "an attribute that is deeply discrediting" (p. 3), determined by a given society in either the literal or figurative sense. He outlined three types of stigma: (1) abominations of the body—including various physical deformities; (2) blemishes of character—based on an individual's behavior or record of institutionalization; and (3) tribal—race, nation, and religion (Goffman, 1963). During socialization the stigmatized individual, "learns and incorporates the standpoint of the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma," and at another phase, "learns that he possesses a particular stigma and, this time in detail, the consequence of possessing it" (Goffman, 1963, p. 32).

Building upon Goffman's work, Burke (2007) posited disadvantage can be perceived as having a stigmatizing effect and results in it occurring as a secondary experience for individuals who associate with others who are disadvantaged. The term "disadvantage" is employed broadly and "viewed as a factor that permeates the experience of people who, perhaps not through choice, are vulnerable or stigmatized, or are in other ways incapacitated in their dealings with the situations and experiences of everyday life" (Burke, 2007, p. 11). Stigma, or disadvantage, are socially constructed concepts that results in some groups being treated differently than other groups based on the lack of culturally desired norms (Burke, 2007; Goffman, 1963).

Burke developed his work upon the experience of siblings of children with a disability and advanced the concept of "disability by association" (Burke, 2004, p. 26, 2007, 2010) rooted

in Goffman's idea of "courtesy stigma" (1963, p. 31). This arises when someone experiences

shame by way of affiliation with a stigmatized individual (Burke, 2010; Goffman, 1963). Burke

(2010) posited that within the context of disability and mental illness, research supported

Goffman's initial concept, resulting in an "associative" (p. 1683) identity placed on family

members from society. Following the earlier work of Östman and Kjellin (2002), Burke (2010)

employed the term "associative" to highlight the negative effect of stigma in place of Goffman's

term "courtesy," posited as potentially misleading for its alternative meaning that suggests

kindness. Burke's (2004, 2010) model (see Figure 1) visually depicts this framework of

"disability by association" and areas with the potential for points of stress in several interactive

exchanges. Specifically, when a child is described as disabled it becomes a family experience,

with particular impact on siblings, which often leaves the nondisabled child feeling a sense of

neglect due to their parents needs to care for the disabled child and subsequently isolated within

the family (Burke, 2007, 2010). Furthermore, their experience with social exclusion often

extends to settings outside the home such as school or peer groups (Burke, 2004, 2010).

However, Burke (2010) posits strengths of the framework that includes opportunities for

empowerment and increased capacity for compassion and empathy.

Burke's (2010) research involved siblings with diagnosed learning disabilities, autism,

cerebral palsy, Down's syndrome and microcephaly. Implications include: increased attention

and understanding to the child without a diagnosis or disability, who perceive themselves as

disabled by their membership in a family with a disabled child; encouraging expression of their

own concerns; and acknowledging their roles and contribution within the family to reduce their

feelings of isolation (Burke, 2010). Burke's (2004, 2010) model is congruent with reports from

parents/caregivers of children who experienced a burn injury expressing similar experiences

(Bäckström, Öster, Gerdin, Ekselius, & Willebrand, 2013; Dillard & Kolomer, 2016; Gullick et al., 2014; Öster et al., 2014).

Based upon the work of Goffman (1963) and Burke (2007, 2010) it would appear the family is not immune to consequences from living with a child experiencing disability, or other construct of disadvantage, and therefore members likely develop their own associative identity or "courtesy stigma." Thus, it seems reasonable to consider whether family members are "burn-injured by association" or even "burn survivors by association" within the burn community? Assuming they are one or both, it is important to inquire how family members—specifically uninjured siblings within this study—negotiate their injured siblings "abomination of the body" into their narratives, as well as associated identity, and make meaning of the experience. The next section will review previous research that explored the impact of a burn injury on the family and uninjured siblings.

Family and Sibling Research within Burn Injury Experience

The literature indicates the unlikelihood for an individual to function in isolation of the systemic dynamics within their family environment (Bronfenbrenner, 1977, 1979; Germain, 1978; Greene, 2009). Additionally, sibling relationships—the first peer group relationship (Caplan, 2011)—are dynamic and foster substantial areas of child development/adjustment and sustain lifelong influence (Bowman, Alvarez-Jimenez, Wade, McGorry, & Howie, 2014; Bretherton, 1992; Brody, 1998; Brody, Stoneman, & McCoy, 1994; Caplan, 2011; Giallo, Roberts, Emerson, Wood, & Gavidia-Payne, 2014). Siblings have the potential to serve multiple roles within the relationship, including teacher/mentor, caregiver, and mediator between parents, while also providing fertile ground to experience a host of emotions, including love, hate, jealousy, admiration, and loyalty (Brody, 1998; Dunn, 1983, 2000). Furthermore, the advances in

medicine and technology introduced earlier position siblings to serve as caregivers for their ill/injured siblings later in life as well (Mancuso et al., 2003). Sibling relationships, studied for over a century, are essential components of the family system, although it has only been in recent decades' greater emphasis was placed on family interests (Brody, 1998; Dunn, 2000; Dunn & McGuire, 1992; Lamb & Sutton-Smith, 1982).

Burn injury research within the framework of extended systems appears relatively untapped—especially when considering the sibling dynamic—extending rich ground to cultivate. The injury seems to shape numerous people in multiple contexts making it unlikely the person who experienced the burn will endure the injury alone (Bronfenbrenner, 1977, 1979; Germain, 1978; Greene, 2009). Though there are efforts to include siblings in family-centered approaches, there remains a dearth in understanding the perspective of routine life and activity from the siblings not impacted by injury or illness (Woodgate, Edwards, Ripat, Rempel, & Johnson, 2016). Qualitative methodologies exploring the impact of a burn injury on the family matured in the literature within the last several years, although interestingly none of the published work reviewed occurred within the United States.

In a review of the empirical literature regarding outcomes for children with burn injuries and their families, Bakker et al. (2013) reported consistent findings connecting the discrete influence of a burn injury on the family system. Part of a larger investigation concerning adults with burns and parents/caregivers of children with burn injuries in the United Kingdom, researchers employed a self-completion questionnaire with family members (siblings, children of adults with burns—identified by their role, not their age—or partners of adults with burns) to explore the impact of the burn injury on themselves and the family—specifically perspectives on the severity and visibility of the burn, difficulties and consequences, and opinions on the family's

support needs (C. Phillips, Fussell, & Rumsey, 2007). Findings suggested the following improvements: extension of psychosocial support to the family system; inclusion of siblings in burn care when appropriate and incorporation of more time with their parents; explanation of anticipated responses and/or emotional reactions following the burn injury; information regarding burn permanence and realistic physical and aesthetic outcomes; and discussion concerning awkward social situations that may arise involving the family member with burn injuries (C. Phillips et al., 2007).

To inform evidenced based recommendations for psychosocial programs in the United Kingdom, C. Phillips and Rumsey (2008) reported on the quantitative portion of a mixed method study exploring the concerns of parents/caregivers of children with burn injuries. Results indicated high levels of clinically significant anxiety and depression for parents with no previous mental health concerns in inpatient and outpatient phases, highlighting the importance of routine sustained screening, as well as ongoing psychosocial intervention (C. Phillips & Rumsey, 2008). Adding to the argument for routine parental screening and interventions, similar findings were reported from Western Australia, with parents also experiencing diminished levels of resilience (McGarry et al., 2013).

Employing a grounded theory design, Ravindran, Rempel, and Ogilvie (2013a, 2013b) explored the experiences of parenting children with burn injuries in India. The first study proposed a three-stage process of embracing survival: (a) suffering the trauma alongside their child who experienced burn injuries; (b) supporting the survival of their child; and (c) protecting the child from stigma precipitated by scarring and disfigurement (Ravindran et al., 2013a). Additionally, parents perceived blame and a lack of support from both healthcare professionals and family members (Ravindran et al., 2013a). The second study examined participants core

process of enduring blame throughout all three stages—injury, wound, and scarring—of their child's burn course, originating from multiple perspectives, such as family members, health professionals, others (e.g. strangers), and the children with burn injuries (Ravindran et al., 2013b). Researchers posited participants conceptualized the process of enduring blame in the following four separate, non-linear stages: internalizing blame, submitting to blame, rising above blame, and avoiding blame (Ravindran et al., 2013b). Consequently, parents sustained a double trauma—not only did they witness their child withstand the physical and emotional pain of a burn injury, but now they suffered the effects of blame related to the injury (Ravindran et al., 2013b).

Gullick et al. (2014) employed phenomenological methodology with a purposeful sample of nine patients and nine family members within an Australian inpatient hospital setting to investigate the understanding of a serious burn injury for both the patients who sustained the physical injuries and their families that extended from acute hospitalization to the early phases of transition into the community. Results suggested the essence included debilitating emotional trauma, conceptualized as a "trauma bubble," which was employed as a "metaphor for the cycle of anxiety and avoidance that contains and restrains communication and emotion for the burned person and their loved ones" (Gullick et al., 2014, p. 418). Patients experienced the structure of the trauma bubble in the way of: physical otherness of burned skin; remembering intense, embodied pain; and recycling the catastrophe (Gullick et al., 2014). Family members constructed their experience through vicarious suffering and the physical difference of their loved one (Gullick et al., 2014). Both the degree and span of the trauma admittedly astonished the authors, who felt confronted by their own previous beliefs regarding who was most exposed to emotional anguish following a burn injury (Gullick et al., 2014). Consequently, their findings highlight the

necessity for coordinated approaches to assess and support both the person who sustained the burn injury, as well as their family members (Gullick et al., 2014).

Similarly, Swedish researchers interviewed six parents/caregivers of children with burn injuries under the age of 18 between 2000 and 2008 (Öster et al., 2014). The authors postulated one ultimate theme—feeling quite alone in striving to regain family wellbeing—based upon four subcategories: difficulties and worries regarding physical problems, altered family relations, changes to everyday life, and need for parental/family support (Öster et al., 2014). These findings support previous work (Gullick et al., 2014) highlighting the critical need for early and continuous care during the acute hospitalization phase, as well as after transitioning home from the hospital.

Dillard and Kolomer (2016) explored the experiences of 11 parents/caregivers of children with burn injuries at a family weekend program offered by a burn foundation in the southeast. Parents communicated a unique experience after their child's injury with shared painful understandings that included: parental guilt, or feelings of responsibility; distressing sensory experiences related to the acute incident and aftercare; isolation; and unknown prognosis, including expectations related to the medical treatment of their children. Feelings of guilt were pervasive, especially regarding the etiology of the child's injury, consistent with Ravindran et al.'s (2013a, 2013b) findings related to blame, or assigned responsibility of fault. Guilt has historically been considered from the maternal position (Bakker et al., 2010; Jackson & Mannix, 2004); however, several fathers vocalized suffering with regard to the culpability of their child's burn injury (Dillard & Kolomer, 2016). Guilt is a complex concept (Baumeister, Stillwell, & Heatherton, 1994) beyond the scope of this paper, but provides important implications for future work. Mirroring other parental experiences in the literature, these participants grappled with

emotions related to being away from their other children, physically and emotionally, following the burn-injury (Dillard & Kolomer, 2016).

Beyond the parents/caregivers, there is a dearth of literature related to understanding the impact for siblings of children with burn injuries. Although a couple of inquiries referenced above included uninjured siblings (Kilburn & Dheansa, 2014; C. Phillips et al., 2007), at present only three studies exclusively inquired into the emotional, behavioral, and social outcomes for uninjured siblings (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003). To my knowledge, the first documented inquiry into the psychosocial adjustment of uninjured siblings utilized nonparametric statistics to compare parent report scores on the Child Behavior Checklist with an age and gender matched reference group (Mancuso, 2002; Mancuso et al., 2003). Additionally, researchers developed and administered the Sibling Injury Impact Questionnaire to distinguish what factors related to the burn injury were impacting uninjured siblings (Mancuso, 2002; Mancuso et al., 2003). Lastly, parents completed the Changes in Behavior Questionnaire, also generated for this study, to assess alterations in the sibling relationship since the injury (Mancuso, 2002; Mancuso et al., 2003). Interestingly, results of the Child Behavior Checklist, used to assess uninjured siblings' psychological and social adjustment, indicated the study group was better adjusted than the normative group in the psychological areas, but they performed worse than the normative group in overall competence, especially social proficiency (Mancuso, 2002; Mancuso et al., 2003). This is not surprising since parents serving as proxies often over or underestimate their child's well-being (Alcantara, Ohm, & Alcantara, 2017; Rimmer et al., 2014). Additionally, contrary to the literature on differential treatment between siblings (Alderfer, Labay, & Kazak, 2003; Bakker et al., 2013; Brody, 2004; Kilburn & Dheansa, 2014; Loeser, Whiteman, & McHale, 2016), uninjured siblings in their

study denied inequity regarding time and treatment from parents, while also reporting ostensibly contrasting feelings that their parents did too much for their injured sibling; however, parents also reported levels of closeness between siblings and protectiveness of the children with burn injuries by their uninjured siblings (Mancuso, 2002; Mancuso et al., 2003). Overall, results did not support uninjured siblings displaying clinical level psychological challenges, and even suggested some benefitted from the experience, which may have implications for posttraumatic growth (Mancuso, 2002; Mancuso et al., 2003; Tedeschi & Calhoun, 1996); however, the authors acknowledged room for further development of several constructs to enhance clarity (Mancuso, 2002; Mancuso et al., 2003).

Conroy (2008) heeded the recommendations of Mancuso's earlier work (2002) and utilized a purely qualitative methodology that employed a phenomenological approach to analyze content from semi-structured interviews with five siblings between the ages of 8 and 18 who had a sibling treated for a burn injury 6 months prior to their enrollment in the study. Conroy (2008) pulled from Mancuso's (2002) earlier work to draft her interview questions. Participants were directly recruited from chart reviews of patients being treated at a children's burn center (Conroy, 2008). Conroy (2008) initially had inclusion criteria with specificity regarding the size of the burn and not permitting multiple siblings from the same family; however, after challenges with locating participants the inclusion criteria was broadened, which finally resulted in ascertaining the five participants. Eight themes were presented after data analysis that included: new experiences for the uninjured siblings; changes in the injured siblings behavior or attitude; changes in the uninjured siblings behavior or attitude; improved family relationships; changes to family routine or structure; worry or sadness about injured siblings by uninjured sibling; increased parental stress; and avoidance or fear of fire or burn agent (Conroy,

2008). Though findings from this study converged in a number of ways with Mancuso's work (2002), such as closer family relationships, uninjured siblings articulating increased worry over their injured sibling, and a lack of differential treatment, they also diverged. Specifically, Mancuso's (2002) findings reported a lack of family disruption, while Conroy's (2008) suggested changed routines that presented obstacles.

Around the same time as Conroy (2008), in a qualitative dominant mixed method research design, Lehna (2008, 2010) explored the consequences of a major burn injury on siblings, primarily from the uninjured siblings' perspective. Although the uninjured siblings were the focus of the investigation, it is worth noting that both parents and injured siblings were also included in the research process (Lehna, 2008, 2010). Uninjured siblings were interviewed in person, as well as over the phone, to elicit information about their experience, although at times parents ended up being the primary source of data (Lehna, 2008, 2010). To facilitate dialogue with non-talkative siblings the Sibling Relationship Questionnaire-Revised was employed (Lehna, 2008, 2010). The essential thematic pattern for sibling relationships in families with injured children—normalization—provided further implications for family centered care's facilitation of adjustment, while concurrently supporting the uninjured siblings' need to sustain a sense of equity within the family system (Lehna, 2008, 2010).

These scholars are to be commended for their pioneering work, which elucidated additional scopes of inquiry, and provide the only basis of knowledge for uninjured siblings; yet, there remains a significant gap in understanding the impact for uninjured siblings. The earliest study relied heavily on quantitative measures with parents as proxies and noted adolescent participants suggested the self-report measure did not sufficiently assess their sibling relationship or probe into significant sibling issues, implicating qualitative approaches to advance deeper

understanding and elucidate more appropriate themes (Mancuso, 2002; Mancuso et al., 2003). Conroy (2008) followed the recommendations of Mancuso (2002) and utilized a purely qualitative study yet reported findings that supported and deviated from that work. Additionally, there were noted challenges to participant recruitment (Conroy, 2008). Lehna (2008, 2010) also echoed Mancuso's (2002) methodological challenges including lack of participant dialogue and the necessity for phone interviews, which resulted in employing a quantitative measure and also utilizing parents/caregivers as proxies.

While research regarding family and sibling experiences after burn injuries is nominal, the literature is replete within the context of chronic illness and disability, suggesting several outcomes for consideration, such as: perceptions of parental bias impacts sibling relationships (Long, Alderfer, Ewing, & Marsland, 2013); healthy siblings face similar stressors of the ill child (Murray, 2000b) and may experience academic, emotional, and social challenges, although parents underestimate difficulties for the healthy sibling (Alderfer et al., 2010; Nolbris, Enskar, & Hellstrom, 2007; Sharpe & Rossiter, 2002); adjustment is positively impacted by social support (Nabors et al., 2013; Zegaczewski, Chang, Coddington, & Berg, 2016); negative interactions with the medical team and an absence of information about treatment and outcomes moderated caregiver stress (Nabors et al., 2013); families experienced a loss as they struggled to define "normal" (Björk, Nordstrom, Wiebe, & Hallstrom, 2011; Björk, Weibe, & Hallström, 2005; West, Bell, Woodgate, & Moules, 2015); and discharging from the hospital lead to a diminished sense of security (Björk et al., 2011). However, encouragingly, findings also supported the adaptability of siblings with chronic health concerns, revealing positive protective factors, such as empathy and compassion, as well as patience and sensitivity (Bellin & Kovacs,

2006). In the final section, research within the context of interventions in the burn community will be detailed.

Intervention Research

As literature in the burn community matures it remains vital that research efforts parallel program development and evaluation. To date, research has focused on burn camps for children who experienced burn injuries, suggesting a positive impact on psychosocial adjustment, social integration, self-esteem, and coping/social skills (Bakker et al., 2013; Bakker, Van Der Heijden, Van Son, Van De Schoot, & Van Loey, 2011; Cox, Call, Williams, & Reeves, 2004; Maertens & Ponjaert-Kristoffersen, 2008; Maslow & Lobato, 2010; McShane, Doctor, Murphy, Blakeney, & Meyer III, 2000; Rimmer et al., 2012; N. R. Williams, Reeves, Cox, & Call, 2004). Additionally, a two-day retreat for individuals impacted by a burn injury and their caregivers demonstrated the program provided value in addressing the mind, body, and spirit during recovery and identifying a need for continuous intervention and education (Kereki et al., 2006). Lastly, although research is growing, support groups for individuals with burn injuries also show value in the literature (Barnett, Mulenga, Kiser, & Charles, 2017; Cooper & Burnside, 1996; Tolias & Chedekel, 2001).

Social support is well documented in the literature as a resource for coping (Solomon, 2004; Wallis et al., 2006) and an important protective factor associated with overall health outcomes (Muangman et al., 2005; Uchino, 2006), as well as adjustment to injury/disability (Gonçalves, Echevarría-Guanilo, Carvalho, Miasso, & Rossi, 2011; Lawrence & Fauerbach, 2003). An extension of this, peer support—when individuals confronted by comparable situations/diagnoses offer their time, understanding, and perspective to benefit others—is also specified as a viable resource to cultivate a sense of community, while likewise acquiring

knowledge to rebuild following trauma (Macvean, White, & Sanson-Fisher, 2008; Solomon, 2004). Moreover, it promotes a sense of feeling "normal," aligning with social comparison theory—the idea that we are pulled towards people we share similarities with in an effort to feel normal (Festinger, 1954; MacNeil & Mead, 2005; Solomon, 2004; N. R. Williams et al., 2004).

Although peer support for individuals impacted by a burn injury is recognized as a potentially distinctive support, research supporting the effectiveness is minimal (Tolley & Foroushani, 2014). Instead, experiential knowledge is discussed in terms of anecdotal benefit for individuals suffering from burn injuries and its perceived efficacy (Acton, 2004; Acton, Mounsey, & Gilyard, 2007; Badger & Royse, 2010a, 2010b; Davis, Gorgens, Shriberg, Godleski, & Meyer, 2014), indicating its presumed utility as an intervention. Unfortunately, this dearth of empirical research often results in discounting the anecdotal or perceived claims (Badger & Royse, 2010a). Therefore, it remains critical that understanding the needs of a burn injury from multiple perspectives provides a catalyst beyond knowledge acquisition into the applied setting.

Chapter Summary

Research within the context of families—particularly uninjured siblings—experiencing a burn injury is well positioned as an area for increased growth, with critical practical implications. Over 45 years ago, Brodland and Andreasen (1974) reported findings with specific implications on the needs of uninjured family members in addition to the patient with the physical burn injuries. Just four years later, Cahners (1978), a social worker at Shriners Hospital for Children in Boston, discussed the importance of group meetings for families of patients with burn injuries during the acute phase of hospitalization, yet the literature suggests little expansion in this area. Recently, Wolfe (2015) called for the burn community to engage a dialogue about the complicated treatments and therapies relinquished over for parents to sustain post discharge,

recognizing there is no evidence to indicate its impact on the family. Beyond the family perspective even less is known about the uninjured siblings experience outside the three studies discussed earlier; yet, literature in other domains of research (i.e. chronic conditions and disability) is replete with research to suggest there are nuances and needs of the siblings without physical illness/injury (Alderfer et al., 2010; Emerson & Giallo, 2014; Giallo et al., 2014; Tasker & Stonebridge, 2016; West et al., 2015; Wilkins & Woodgate, 2005; Woodgate, 2006b, 2006a; Woodgate et al., 2016).

Therefore, acquiring direct insight from the uninjured sibling perspective advances knowledge and will likely reveal other critical areas in need of consideration. Additionally, from an applied position, this understanding provides utility concerning implications for the development and/or enhancement of programs/services. Though burn injury consequences are expansive, the aim of this study was to employ narrative inquiry (Riessman, 1993, 2008) to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. The following chapter will detail the research methodology employed in this study to further understand the stories of uninjured siblings, within the context of a burn injury.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

Introduction

Chapter 2 provided a review of the literature to highlight knowledge supported by earlier scholarship, as well as recognize opportunities that warrant further investigation. Chapter 3 will outline the methodology used to guide the current study. It commences with a brief assessment of the current scope of knowledge, as well as the study's purpose and research questions. Thereafter, the following areas will be addressed in detail: 1) Subjectivity Statement; 2) Research Design; 3) Methodological and Theoretical Paradigms and Frameworks; 4) Methods of Data Collection and Analysis; 5) Strategies to Assess Data Quality; and 6) Limitations.

Creswell (2013) stated, "[W]e conduct qualitative research because a problem or issue needs to be *explored* [emphasis in original]" (p. 47). As highlighted in Chapter 2, although three scholars (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) investigated the psychosocial adjustment and experiences of uninjured siblings, a crucial gap exists regarding the unique perspective elucidated through their own words and stories. Qualitative research allows us to ascertain a complex and detailed description of the issue that may otherwise be missed in quantitative research styles with measures and analysis that do not "fit the problem" (Creswell, 2013, p. 48).

As noted by Mancuso (2002) and Mancuso et al. (2003) attempts to understand the experience of uninjured siblings using quantitative measures did not adequately measure sibling relationships or significant issues they faced resulting in recommendations for the use of

qualitative methods. Lehna (2008, 2010) employed a qualitative dominant mixed-method design but noted challenges to engaging the uninjured siblings and subsequently used parents as proxies, in addition to a quantitative instrument. Around the same time as Lehna (2008, 2010), and based on earlier recommendations, Conroy (2008) conducted a purely qualitative study and interviewed five uninjured siblings. Results aligned and deviated from earlier work, in addition to presenting new areas of interest. As an understudied area, this study presented uninjured siblings—specifically adults taking a retrospective approach—an opportunity to share their realities and interpretations in their own words, and also provided a chance for them to feel empowered as the expert on the subject and have their experience recognized (Creswell, 2013).

Consequently, the purpose of this study was to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. As previously stated, there is a dearth of research exploring the perspective of uninjured siblings that does not utilize quantitative instruments or proxies; therefore, the intent was to gain a first-hand account from uninjured siblings as the experts of their narrative. Engaging adults through a retrospective method allowed a more integrated perspective of the experience and also illuminated implications on their identity. The study was guided by these central questions:

1. What are the experiences, or stories, of identified adults whose sibling experienced a burn injury?

2. What do the narratives of identified adults whose sibling experienced a burn injury reveal about how their identities were shaped?

3. What are the implications for program/service development and/or enhancement elucidated by identified adults whose sibling experienced a burn injury?

Subjectivity Statement

Subjectivity is embraced in qualitative research (Peshkin, 1988) with an understanding that there is no pure or uncontaminated data, but rather interpretations made by participants answering the questions and/or researchers writing up their findings (Freeman, deMarrais, Preissle, Roulston, & St. Pierre, 2007). Victor Frankl (1959) grappled with the practicality of "detachment" (p. 6) when writing about his experience as a prisoner in Nazi camps. He posited:

> [D]oes a man who makes his observations while he himself is a prisoner possess the necessary detachment? Such detachment is granted to the outsider, but he is too far removed to make any statements of real value. Only the man inside knows. His judgements may not be objective; his evaluations may be out of proportion. This is inevitable. (Frankl, 1959, p. 6)

Instead, Frankl (1959) argued for attempts to eschew personal bias. Qualitative inquiries typically include a subjectivity statement—one tool in that attempt—that provides information about the researcher's background, including their relationship to the area of study, advanced through their professional experience, worldviews, and individual histories (Preissle, 2008). These statements aid in the identification of researchers' own personal feelings/beliefs and predispositions that could influence their research, while also providing the reader points of consideration regarding the study's credibility, authenticity, and overall quality (Preissle, 2008).

My Subjectivity Story

As indicated above, subjectivity statements are common in qualitative research (Preissle, 2008). For this study, I choose to approach this statement in line with the narrative method (Riessman, 1993, 2008) and offer subjectivity through the lens of my own story as a researcher; thus, this section may be more detailed than traditionally anticipated. However, I felt if I asked

my participants to be vulnerable and thorough in sharing their experiences it was equitable for me to do the same. As such, my story is also recognized as fluid and a representation of my understanding of reality and interpretations at this point in time (Riessman, 1993, 2008) and is expected to evolve as stories do (McAdams et al., 2006). Furthermore, I found the opportunity to highlight the personal influences of my narrative meaningful as many participants reported during member checking (Jirek, 2016).

    My story begins almost 20 years ago with a sign-up sheet outside a professor's door. I was a nervous first year social work graduate student brimming with uncertainty and doubting when, where, or if I would locate myself in the field. Gratefully, an innovative professor with a family connection to burn trauma developed a course in collaboration with a burn foundation I was excited—yet terrified—to explore. She held a meeting with interested students and advised us the course entailed seven days at an overnight summer camp for children with burn injuries— later known to me as "burn camp"—as well as course readings, response papers, a daily journal, and class group meetings, in addition to the organizations volunteer staffing expectations. Although I was excited about the opportunity to acquire "hands on" experience and receive course credit for attending camp, I was overwhelmingly anxious about working with a population of children described as "scarred" and "disfigured." In a culture bound by aesthetics, angst revolved around my ability to navigate the physical differences and still see—and engage—them as children foremost. As fearful as I was about their arrival the first day of camp, I distinctly remember the moment the first busload of campers pulled in—kids bounded from the vehicle with laughter, smiles, and water balloons in a fury of excitement to reunite with campers and counselors. It was in that moment I remember exhaling and saying to myself, "they are just

kids." I relaxed into the realization I would likely stumble and make mistakes—both at camp and as a social work professional—but at the end of the day I would be fine.

The following year I graduated and began work as a medical social worker followed by a school social worker, yet every summer I returned to the beloved burn camp. Eight years after my first summer at camp, that same burn foundation hired me as the Programs Director, where for 11 years my responsibilities involved the design and implementation of multiple programs and services within the burn community and fire service, including: retreats for young adults with burn injuries; family weekend programming for individuals impacted by a burn injury and whoever they defined as their family; college scholarships; conference sponsorships; fire department grants; fire safety and prevention programs; and community presentations and trainings. I initially managed the summer camp program when I began with the organization; however, my responsibilities evolved to concentrate on the development of adult and family-oriented programs.

That said, I continued to attend camp where my sole role was the clinical social worker providing psychosocial support/intervention. I just completed an eight-year board term board for the International Association of Burn Camps, where I served as Board Chair my last two years. Additionally, I served as the Secretary for the Federation of Burn Foundations. Lastly, I currently serve an appointed position on the Aftercare and Reintegration Committee for the American Burn Association, as well as co-chair the Psychosocial and Burn Survivor and Reintegration Special Interest Groups for their annual meeting. Through these professional responsibilities, I routinely collaborate with other burn foundations and fire service professionals in the United States and Canada, which appreciatively broadened my perspective beyond the local vantage point.

My 20-year immersion—first as a student/volunteer and later as a licensed clinical social work professional—positioned me to experience and discover the community directly. In my early years, as someone new to the burn community, acquiring knowledge and understanding about the physical and psychosocial trauma for individuals who sustained the physical injury took precedence. However, I recognized—both intuitively and intellectually—neglecting the family component seemed a stark oversight. This awareness was further advanced during the burn foundation's inaugural family weekend program five years ago. During the weekend families, including uninjured siblings, were in a space that welcomed and encouraged them to talk about their experience, which many did with ease. This anecdotal evidence rested heavy on my head and heart, which then became pervasive when I considered programming and research moving forward. Furthermore, I found myself keenly aware of how interventions primarily targeted individuals with the physical trauma, rendering the support system secondary, if acknowledged at all. My heightened sensitivity to the needs of the support system facilitated enhanced recognition for how they were included or discussed, which frequently seemed to be within the context of how they could better support the person with the physical injury, again seemingly overlooking their unique experiences/needs. I remember attending a workshop at a major burn conference where family/caregivers were referred to as "coaches" for the person with the burn trauma, and I thought to myself, "Who is there to coach and support them?"

Needless to say, I never expected to learn as much as I have about the burn community or myself. Much of this knowledge has been attained via informal observations and conversations. It is through these privileged personal glimpses into the impact of burn trauma I developed a profound awareness regarding the uniqueness of burn injuries, beyond the individual physically injured, to the encapsulated bystander—be it family/caregivers or first responders. The

importance of sibling relationships goes without saying. After becoming better acquainted with the nuances of burn injuries and developing rapport with individuals and their systems, I was reminded of the critical importance regarding the interconnectedness of experience.

Therefore, I enter this study colored by my extensive history in the burn community where I am admittedly predisposed towards those who did not sustain the physical burn trauma, but whom I believe also live with scars—those unseen by the eye—that go unacknowledged. Furthermore, I am impassioned by a sense of responsibility to advocate for them in the wake of my experiential knowledge. This drives my commitment to attain a greater understanding about the systemic impact of a burn injury, for both knowledge acquisition, and, as a 20-year clinical practitioner, more critically for pragmatic application through the enhancement/development of programs/services. Specifically invigorated by the desire to acquire stories of siblings impacted by a burn trauma in childhood, qualitative research provides an appropriate methodology. I echo Morrow's (2007) sentiments about her own relationship with qualitative research, "I gravitated quite naturally to qualitative methods because I believed they would enable me to understand the meanings that oppressed peoples made of their experiences and give voice to people who had traditionally been marginalized, made invisible, or silenced" (p. 210). However, I acknowledge the role I play as the researcher making choices around interpretation and representation of said voices (Mauthner & Doucet, 2003) and agree I "cannot *give* [emphasis added] voice, but we do hear voices that we record and interpret" (Riessman, 1993, p. 8).

In addition to the professional subjectivities outlined above, I must also take a moment to highlight personal influences on this research, definitely still raw as I outline them here. Two interviews into data collection, my mother became ill and was subsequently diagnosed with stage four cancer that had metastasized to her brain. Needless to say, the days, weeks, and months

following that diagnosis became terrifying and lonely, which left me with a new—and quite

honestly unsolicited—appreciation for the gravity of an acute medical condition's impact. I felt

that I was living the clichéd idiom of "hanging on by a thread." The traumatic impact of a

medical diagnosis/injury was not "new" information to me. During my 20-year career as a social

worker, I have worked in hospitals and/or other settings where medical crises were a somewhat

routine part of the job; yet, facing the reality and daunting news for my own mother's prognosis

was unequivocally breathtaking.

For the next several months, I became the primary caregiver of my mother—an

opportunity I will always treasure—while trying to convince myself, and others, that I was

"okay." I am not inclined to distinctly solicit help—I get that sense of independence from

mom—so the idea of being vulnerable by asking for help and sharing my thoughts, fears, and

emotions, around something I knew was completely out of my control was far from easy. It still

is not. I just went into "do" mode. My mother died almost 3 months after her diagnosis, and I

knew the difficult times were far from over. Needless to say, I still—and will always—grieve the

loss of my mom while simultaneously trying to figure out what life's "new normal" is for me.

During my mom's illness and death I found myself surrounded by well-intentioned

friends and family who searched for words to comfort me—and I am grateful to have so many in

my life; yet, I struggled to find people who truly understood what I was going through or were

comfortable watching me sit [quite literally for days and weeks at both the hospital and hospice]

in pain and grief. The value of having someone in my life who had been through a similar

experience—in my case losing a mother to cancer—crystallized to me in a very personal way. I

found solace being able to talk with them in a way that felt less guarded and did not seem to

require the same amount of explanation. It became a different kind of support; one I did not realize would hold so much value to me during my ongoing journey with grief.

Therefore, I am also mindful of personal influences on this study—unexpectedly acquired—through ongoing reflections about enduring a loved one in pain and distress during a medical/health crisis, while also feeling unsure what do, but just wanting to make it better. First, I realized my thoughts echo similar messages heard in my years of work in the burn community regarding the value of peer support and what I—seasoned practitioner and novice researcher— perceived was missing for the family, particularly the uninjured siblings. Through my firsthand involvement with peer support my endorsement for its utility was deepened. Additionally, my experience allowed me to understand in a very personal way, why opening up—even to people you love and care about—can be difficult during a crisis. I appreciated guarding my emotions in an attempt to inoculate those I loved by trying to "stay strong." Lastly, as I began—and continue—to evolve through the grief, I recognized I was embracing an altered worldview and realized I also interpreted life in new ways. The above considerations ostensibly predisposed my approach to interviewing the remaining five participants, as well as data analysis, with attention to managing crisis and meaning-making.

Research Design

This study utilized narrative inquiry to explore the stories of uninjured siblings (Riessman, 1993, 2008). Put simply, "[N]arrative inquiry is stories lived and told" (Clandinin & Connelly, 2000, p. 20). This qualitative approach is concerned with understanding and honoring the lived experience (Clandinin, 2013) through a "collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin & Connelly, 2000, p. 20). Narrative inquiry is "an experience of the

experience…people in relation studying with people in relation" (Clandinin & Connelly, 2000, p. 189). Attention to chronology distinguishes narrative analysis with researchers focused on specific actors, social places, and social times, while questioning both intention and language—not just the content of the story, but how and why events are storied (Riessman, 2008). In other words, the story is thought of as what happened, while the narrative becomes how the experience of telling what happened is structured for a purpose (Riessman, 2008). Researchers consider: who the story was constructed for and its purpose; why events are sequenced in a certain way; what plots unfold; what cultural resources are, or are not, employed; what is achieved by the story; and do discrepancies or holes appear that could imply a divergent or favorable version (Riessman, 2008).

Identity is central to narrative inquiry, whether through the lens of identity construction (Clandinin & Huber, 2002; Riessman, 2002, 2008) or accessing different versions of one's inner self (Crossley, 2000; Josselson, 1995). According to Riessman (2002), "Narratives are a particularly significant genre for representing and analyzing identity in its multiple guises in different contexts" (p. 706). This allows researchers to study personal experiences in-depth to understand how important events have been constructed by participants (Riessman, 2002, 2003). When considering the research purpose, I remained aware of the "So what?" and "Who cares?" questions often poised, particularly to narrative inquirers, due to misperceptions about the simplicity of the methodology, as well as anecdotal outcomes (Clandinin, 2013).

Thus, it was critical to consider: 1) personal justifications—locating the study within the context of my life experience for awareness of who I am, or may become, and how my own stories impacted the process and my response to participants; 2) practical justifications—being aware of critical implications for how the study could shift practice; and 3) social justifications,

including theoretical for knowledge building and social action for policy implications (Clandinin, 2013). To better appreciate the lived experiences of uninjured siblings, yet to be elucidated, narrative inquiry offered a chance for in-depth appraisal of stories and meanings to understand how individuals constructed significance from the burn injury incident and the influence that specific incident had on their identity (Riessman, 2002, 2003). J. Phillips, MacGiollaRi, and Callaghan (2012) claim, "Research is the ultimate telling of a story" (p. 785). When it came to the lived experience of uninjured siblings there were certainly stories waiting to be told.

However, in closing, it is also important to consider critiques of narrative inquiry. Connelly and Clandinin (1990) caution researchers how easily narratives could be manipulated and potentially result in deception, making the ethical obligations crucial, including "ownership" of the story (Clandinin, 2013). Narrative is also a "slow and painstaking" (Riessman, 2002, p. 706) process—usually over long periods of time—requiring keen attention to details and nuances in language, including the complexity of its treatment, social/cultural/historical contexts, and story organization (Gilbert, 2002; Riessman, 1993, 2002). Lastly, researchers may find the process emotionally taxing if dealing with repeated exposure to stories that include suffering and grief/loss (Gilbert, 2002) therein making vigilance to vicarious trauma essential for personal wellbeing (Connolly & Reilly, 2007; Kiyimba & O'Reilly, 2016; Rager, 2005).

Narrative Research and Social Work

Scholars contend the utility, yet underutilization, of narrative inquiry in social work research as an applied field (Larsson & Sjöblom, 2010; Riessman & Quinney, 2005). Narrative is often embraced within social work practice (Roscoe, Carson, & Madoc-Jones, 2011); yet, the profession seeks to understand human behavior and change within specific contexts, which creates space to argue for greater use of narrative as a natural way to advance knowledge within

education and research (J. Phillips et al., 2012). Furthermore, human interaction is essential to narrative research and also a core value within social work (National Association of Social Workers, 2017). Concentrating on participant/client stories and providing a mechanism to promote these stories, especially to marginalized groups, is a key tenent to both narrative research and social work (Larsson & Sjöblom, 2010; Riessman & Quinney, 2005).

Methodological and Theoretical Frameworks

It is proposed Michael Connelly and Jean Clandinin developed narrative inquiry in their attempt to understand experiential knowledge of teachers' (Connelly & Clandinin, 1990; Wang & Geale, 2015). Although originally conceived as phenomenon and method, it was quickly realized a methodology, with philosophical foundations in Dewey's theory of experience (as cited in Clandinin, 2013, p. 12) and fundamental views of experience as relational, continuous, and social (Clandinin, 2013). However, exact origins are disputed as some posit beginnings with Susan Chase in Chicago School sociology in the early twentieth century, while others suggest roots in the move from realism in the 1960s (Riessman, 2008). Irrespective, it has broadened to include approaches grounded in psychology with psychodynamic perspectives (Crossley, 2000; Josselson, 1995; Lieblich & Josselson, 1994), as well as sociology with social constructionism and postmodern perspectives (Crossley, 2000; Riessman & Quinney, 2005). Although typically grouped together under the name *narrative inquiry*, these perspectives vary, and as such, inform methodology from their unique standpoint (Clandinin, 2013). As a researcher who identifies with the social constructionist position, I relied primarily on Riessman's (1993, 2008) approach to narrative inquiry through the lens of narrative identity (McAdams, 2018; McAdams & McLean, 2013), which are both explored in greater detail below. Therefore, the study was grounded in social constructionism, which seeks to understand the world in which individuals live (Schwandt,

2000; Witkin, 2012), and further informed by McAdam's (1985) framework of internalized and evolving life stories known as narrative identity.

Social Constructionism

Social constructionism could be considered a development as part of the postmodernist movement following World War II that rejected religious dogma and recognized beliefs are constantly changing (Witkin, 2012). Defining the framework presents a challenge due to underlying assumptions and opposition to precise definitions that social constructionists find limiting and authoritative (Witkin, 2012). However, according to Guba and Lincoln, it begins with the foundation that the human world differs from the physical world (as cited in Patton, 2015, p. 121) and as such, cannot be directly observed, but must be interpreted (Haverkamp & Young, 2007; Schwandt, 2000). Ontologically grounded in relativism, it posits the idea of multiple equally valid realities over one single truth (Guba & Lincoln, 1994; Schwandt, 2000). It recognizes individuals employ interpretative assumptions based on their own experiences and context to describe or make sense of the world in which they live (Gergen, 1985; J. C. Hall, 2014) with an understanding that knowledge is historically, culturally, and socially contingent (Witkin, 2012).

Additionally, language is a fundamental force that manifests reality (Witkin, 2012), which assumes the "plurality of observers implies a potential plurality of observations and accompanying descriptions" (Michailakis & Schirmer, 2014, p. 432). Therefore, the goal is to understand lived experience from the distinct viewpoint of the individual actually living it, while also recognizing historical influences and their role in evolving perspectives and definitions of the self (T. Andrews, 2012; Gergen, 1985). Essentially, "[W]hat is perceived as real is real in its consequence," and accordingly, has implications for where individuals are located and the

context in which they operate (Patton, 2015, p. 121). Epistemologically, the multiple realities are co-constructed through interaction between individuals rather than discovered (Guba & Lincoln, 1994). Furthermore, researcher values are ineluctable, and as such are honored and negotiated with the research (Guba & Lincoln, 1994). Attempts to eliminate values would be viewed as prejudicial regarding the interests of the emic perspective and the integral role of subjectivity (Guba & Lincoln, 1994).

The strengths of social constructionism lie in its application to social work research and practice (Blundo, Greene, & Gallant, 2009; J. C. Hall, 2014; Hutchison & Charlesworth, 2011; Michailakis & Schirmer, 2014). It challenges social workers to "surrender the role of expert" (J. C. Hall, 2014, p. 9) and appreciate the possibility for multiple truths, while becoming an active participant in understanding and accommodating diversity of individuals (Blundo et al., 2009). Criticisms of the approach include: a lack of clarity in concepts and difficultly operationalizing for research; disregard for the larger context of society and power—suggesting the focus on multiple meanings and perspectives diminishes oppression to the appearance of a small difference; and minimization of biological influences (Hutchison & Charlesworth, 2011; C. C. Williams, 2006).

Narrative Identity

According to McAdams and McLean (2013), "Narrative identity is a person's internalized and evolving life story, integrating the reconstructed past and imagined future to provide life with some degree of unity and purpose" (p. 233). McAdams (1985, 2001) originally conceived this as the life story model of identity, with the assumption that as individuals live their lives and continue to develop and acquire knowledge their identity, or life-story, evolves as does their awareness of the self, environment, and roles/relationships. There are two primary

approaches to exploring the development of identity derived from Erikson (1963, 1968)—

identity status and narrative (McLean & Pasupathi, 2012). Considering identity through the lens

of crisis and resolution is a process that is status oriented with the most advanced form of

identity development being identity achievement (Erikson, 1963, 1968; McLean & Pratt, 2006).

Alternatively, narrative places emphasis on life span development and psychobiography

(McAdams, 2001; McLean & Pasupathi, 2012; McLean & Pratt, 2006; J. A. Singer, 2004) to

answer Erikson's (1963, 1968) key identity question: Who am I? The framework recognizes the

dynamic process engaged in one's life story that is constantly being revised with new

experiences (McAdams, 2001). In this regard, "[N]arrative is not just a methodology but is, more

importantly, a construct; it is not that the self is measured by assessing stories, but rather the self

is [emphasis in original] a story" (McLean & Pratt, 2006, p. 715).

Integrating, or making sense of, one's experiences is a primary characteristic of

knowledgeable life narratives (McLean & Pratt, 2006). There are various definitions employed

within narrative identity research of this quality (e.g. accommodation, exploratory processing,

integration, integrative memories, and meaning-making) (McLean & Pratt, 2006). Though the

language may vary, they all share the use of autobiographical reasoning (Habermas & Bluck,

2000) when considering one's life experience. Autobiographical reasoning involves "creating

relations between different parts of one's past, present, and future life and one's personality and

development" (Habermas, 2011). Or put simply, it can be thought of as the ongoing formulation

of our narratives (Tarp, 2018). It is not just the act of remembering, but explicitly entails

reasoning to highlight the importance of the following three areas: constructing and interpreting;

cognition and communication; and implications for reason and logic (Habermas, 2011).

Meaning-making requires that individuals advance past specific threads and details in their

stories to verbalize what their story means about who they are (McAdams & McLean, 2013). Furthermore, narrative identity posits that although it may not always be realized, individuals do attempt to learn and grow by storying their experiences (J. A. Singer, 2004).

Stories can vary depending on the situation and the listeners, developing through social interaction and relationships that are ultimately "performed in presence of certain audiences" (McAdams et al., 2006, p. 6). Well suited in tandem with a social constructionist perspective, narrative identity is not concerned with the accuracy, or truth per se, of life stories (McAdams & Guo, 2015). Instead, it assumes the accounts are likely selective and biased reconstructions of the past (McAdams & McLean, 2013) that suggest what an individual conceives the past to be at that point in time, instead of what it may have actually been (McAdams & Guo, 2015). Furthermore, McAdams and Guo (2015) posit the inaccuracy of depictions is the primary epistemological reason for systematic research into an individual's narrative identity. It is only through these subjective narratives that researchers are provided a glimpse into an individual's life purpose and meaning, as well as the capacity a person has to manage life's challenges (McAdams & Guo, 2015).

Singer (2004) argues the frameworks view that identity cannot be reduced to a particular set of psychodynamic forces (e.g. Freud, Alder, and Jung), but rather supports theoretical notions that see individuals as meaning-seeking is both its greatest strength and weakness. He suggests the absence of reductionist theories allows researchers to embrace how stories emerge while fostering sensitivity to sociocultural contexts (J. A. Singer, 2004). However, in the absence of a fundamental organizing principle narrative identity researchers may provide more descriptive accounts of identity versus explanatory (J. A. Singer, 2004). Still, McAdams (2012) maintains the utility of narrative identity remains steadfast to multiple domains of psychological research—

including developmental, cognitive, cultural, social, personality, and clinical—within the context

of both discovery and justification through the advancement of the framework over the years. As

such, narrative identity provides a fitting framework for this study's emphasis on elucidating

individual accounts, as well as exploring the stories for broad themes and identity implications.

Methods of Data Collection and Analysis

After outlining the rationale for qualitative methodology used to address my research

topic, discussing my potential bias as a researcher, identifying the research design, and defining

my methodological and theoretical paradigms, I will now focus on describing data collection and

analysis. Specifically, this section will address: 1) sample selection, recruitment, ethical

considerations, and risks and benefits; 2) data collection and data management; and 3) data

analysis.

Sample Selection, Recruitment, Ethical Considerations, and Risks and Benefits

The following section will further specify the rationale and procedures for sample

selection, recruitment, ethical considerations, and risks and benefits in greater detail.

Sample selection. Riessman (2008) argues narrative methods "are not appropriate for

studying large numbers of nameless, faceless subjects" (p. 18). Therefore, a smaller sample size

was employed to capture the details of a small number of individuals (Gilbert, 2002; Riessman,

2002). Estimating an appropriate sample size—conceptualized as the number of individuals,

interviews, and/or observations—is debated and unclear within qualitative research (Morse,

1995, 2015; Onwuegbuzie & Leech, 2007; Sandelowski, 1995). Sandelowski (1995) posits the

following principle:

An adequate sample size in qualitative research is one that permits—by virtue of not

being too large—the deep, case-oriented analysis that is a hallmark of all qualitative

inquiry, and that results in—by virtue of not being too small—a new and richly textured

understanding of experience. (p. 183)

Data quantity is not as important as "information-rich cases" (Patton, 2015, p. 264) that allow

researchers abundant knowledge concerning the central issues of importance to the purpose of

the study (Sandelowski, 1995). As such, qualitative approaches typically involve purposeful

sampling (Patton, 2015; Sandelowski, 1995).

An appropriate sample size for phenomenological research, such as narrative inquiry, can

range from six to 12 participants, provided thematic repetition after six narratives (Beitin, 2012;

Kim, 2016). However, theoretical saturation is becoming the most shared approach to sample

size (Kim, 2016), another critical, yet often contentious subject and vital component to rigor

(Morse, 1995, 2015). According to Morse (2015), saturation is facilitated by sampling that is

adequate or large enough for replication—as well as appropriate—and accomplished by

interviewing experts in the phenomenon of interest. Additionally, it is connected to the

researchers' adeptness when asking questions, their sensitivity and experience, understanding of

theory and the literature, and skill with data analysis/interpretation (Morse, 2015).

A purposeful criterion sampling method (Onwuegbuzie & Leech, 2007; Patton, 2015)

was employed in order to obtain a sample of seven participants; however, it became necessary to

employ sequential and emergence-driven strategies, such as convenience or snowball sampling,

in addition to criterion sampling due to the methods strength in accessing populations that are

unknown (Noy, 2008; Onwuegbuzie & Leech, 2007; Patton, 2015). This type of sampling, which

involves accessing potential participants through other informants, is the most utilized method in

social science qualitative research as either the primary source—argued as a technique worthy of

utilization "*on its own right and merit* [emphasis in original] and not as a default

option…deliver[ing] a unique *type of knowledge* [emphasis in original]" (Noy, 2008, p. 331)—or as a supplementary method to enhance sampling.

     Selection criteria. Criterion sampling requires all cases meet some standards established during the design of the study (Onwuegbuzie & Leech, 2007; Patton, 2015). Inclusion criteria for uninjured siblings was as follows: (a) adults (19 years of age or older) who through family membership—broadly defined as the "group of persons with whom one shares a bond of connection by virture [*sic*] of blood, marriage, adoption, or long-term commitment" (J. M. Patterson & Garwick, 1994, p. 13)—have a brother or sister who sustained a burn injury that resulted in either inpatient or outpatient hospital treatment settings; (b) siblings must have both been minors (under the age of 18) for at least two years following the burn injury and (c) lived together at the time of the burn injury, regardless of family membership; (d) the burn injury was not related to abuse and/or neglect; and (e) they are proficient in spoken English and (f) free of any developmental or cognitive diagnosis. Therefore, in the context of this study, uninjured siblings were adults 19 years of age or older who acknowledged a sibling relationship based on biology, marriage, adoption, or long-term commitment, to a brother or sister treated for an accidental burn injury, regardless of the etiology (e.g. thermal, chemical, electrical, or friction) or burn assessment (e.g. location, total body surface area percentage, or degree) in either inpatient or outpatient hospital treatment settings, and they both lived together for at least two years as minors after the injury. However, one participant was an exception, which is discussed below.

     Although previous research with uninjured siblings included criterion regarding the length of time since the burn injury (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003) this study remained open to a range of durations to gain varied perspectives. Furthermore, classification of injury severity (i.e. burn depth and percentage of

total body surface area burned) in relationship to psychosocial impact is questionable (Gullick et al., 2014; Mancuso et al., 2003); therefore, that information was not part of the inclusion criteria, but rather collected as a point of reference. Present-day adolescent sibling relationships are certainly relevant and significant to consider but were beyond the scope of this study and should be considered for future research.

Six of the seven participants met all the inclusion criteria as outlined. However, due to ongoing recruitment struggles explained below, the decision was made, in consultation with my major professor, to include participant seven in the study even though he was not alive at the time of his sister's injury. Therefore, he did not meet criteria (b) and (c) as outlined above. After almost a year and a half of soliciting participants in the burn community the decision to permit his participation—noting his altered circumstance—and conclude recruitment occurred concurrently.

Recruitment. Suzuki, Ahluwalia, Arora, and Mattis (2007) argue part of a research project's success is dependent upon knowing and accessing communities where data will be collected. My involvement with the burn community and professional responsibilities as Programs Director for the burn foundation facilitated a natural point of access after verbal agreement from the Executive Director to support my research (D. Gardin, personal communication, February 20, 2017). I consulted the Phoenix Society for Burn Survivors—a national nonprofit working with the burn community—and received permission (see Appendix C) to use one of their images in two different forms of recruitment materials: 1) a poster (See Appendix D); and 2) a social media post (See Appendix E). Recruitment began via the burn foundation, as well as other professional channels, May 2017 and ended with the final participant interview November 2018. However, there was a hiatus in active recruitment from November

2017 to April 2018 due to the personal circumstances shared earlier; still, the information that had previously been disseminated remained circulating in the burn community.

Specifically, recruitment strategies included social media posts that were shared via Facebook to the following: my personal page; friends pages' who are engaged in the burn community; the burn foundation's page; a local burn center's page; and burn community group pages. The initial post was periodically reposted on several of the pages noted above. The flyer was forwarded by a licensed clinical social worker to a clinician's list serve. I also verbally recruited at various programs and/or professional conferences I attended, such as: young adult retreat; burn camp; family weekend; American Burn Association annual conference; World Burn Congress; and the International Association of Burn Camps Workshop. Furthermore, a social work colleague who lives in Canada distributed the poster at the Canadian Burn Survivors Conference. Additionally, I emailed several professional colleagues—academic and practitioners—the flyer and a brief description of the study, which they then shared with their local burn communities in others area of the country.

Although my entry into the burn community was straightforward with well-established professional connections, I forecasted challenges gaining access to uninjured siblings, particularly adults. Still, it was more difficult than expected. I speculate this was primarily due to the lack of programs/services for uninjured siblings, which left them disengaged from the burn community and my primary location for recruiting. Therefore, due to this historical absence of programmatic and/or research consideration, participants in this study were most frequently (n=5) accessed via their injured siblings who were engaged in the burn community (i.e. convenience or snowball sampling). The remaining two participants were recruited via colleagues in the burn community who shared the study details with uninjured siblings they

knew. The uninjured siblings granted permission to my colleagues to share their contact information with me so that they could learn about the study, as well as determine eligibility and willingness to participate. The challenge I encountered locating uninjured siblings to elucidate their narratives in tandem with the statistics discussed earlier around childhood burn injuries is arguably another reason for the importance of the study. Furthermore, Alyssa commented during her interview, "You don't know how to contact [uninjured] siblings, we don't have a support group, no [*sic*] Facebook page or anything, you just kind of find each other."

Multiple attempts were made to recruit via social media outlets, as well as through other professional relationships; yet, no one contacted me as a result of these attempts, and in the end in came down to a very organic approach to locating participants (i.e. convenience or snowball sampling). Even so, employing injured siblings in the recruitment process provided interesting insight. For example, after I explained the context of the study, several injured siblings commented that they had never talked with their uninjured sibling about the experience, much less what it was like for them. They expressed discomfort about sharing the research opportunity with their uninjured sibling since it could potentially start a dialogue they had not considered.

Yet, there were a couple of injured siblings who agreed to present the research opportunity to their uninjured siblings, which also provided noteworthy information. One of the injured siblings—known to the me for about 15 years—reported back that since their uninjured sibling did not know me, they were not comfortable talking to me. It is possible the uninjured sibling could have perceived my extensive history with their sibling as an inequity going into the interview; though, there were other participants in the study whose injured siblings were known to me for a number of years. Or, it could be they simply did not feel comfortable or ready to engage in a dialogue. Another injured sibling advised her uninjured siblings were "not open at

all" and indicated they were the only individual in the family who talked about it; though, it was unclear if the uninjured siblings were ever presented the opportunity. Lastly, four participants who initially agreed after being presented the specifics from their injured siblings and got far enough in the process to determine they met the criteria, either later declined or did not respond to subsequent communication. Of the two who declined, one indicated they did not have the time, and the other stated that due to perceived discrepancies between the siblings' personal accounts they did not want to consider discussing the subject at all.

After potential participants were identified they were initially contacted via phone call, email, or text message. This initial contact determined their interest in learning more about study. If participants agreed to learn more, they were next contacted by phone or email based on considerations to geography and time zone. Over the phone, their consent was obtained via the Telephone and Eligibility Screening and Consent Script (see Appendix F) and their eligibility was subsequently established. Participants who were communicated with electronically were provided this information via email and their eligibility was established by written expression of their answers to the eligibility questions. During both instances, participants also learned about the purpose of the study, as well as their rights as a participant. Once participants eligibility and agreement to participate was confirmed—as well as addressing any questions—we discussed the best day/time and location for the interview. Due to varied geographic locations and time zones technology assisted modalities were required for several of the interviews, which will be discussed in greater detail below.

Ethical considerations. Participants rights were safeguarded in a number of ways. This research proposal was approved by my dissertation committee on April 27, 2017. Additionally, the University of Georgia's Institutional Review Board also approved the study on April 25,

2017 (see Appendix G) and a subsequent modification of data collection to include artifacts—

discussed later—on July 7, 2017 (see Appendix H). Furthermore, each participant was provided

a copy of the informed consent (see Appendix I) for their personal records. Participants who

were interviewed in person were provided two copies at the time of the interview—one to sign

and one to keep. Additionally, I reviewed the material covered in the document before

commencing the interview. Participants in distant locations were emailed an electronic copy of

the informed consent and/or mailed two copies—one to sign and one to keep. Their signed

informed consents were collected prior to the interview and the material was also reviewed at the

start of their technology assisted interview. Participants signed consent forms were scanned and

stored electronically in a password protected cloud drive (e.g. Dropbox and Google Drive), as

well as my password protected computers. Originals also remain in the possession of the

researcher. Per the American Psychological Association, consent forms and data will be kept for

a period of six years (University of Georgia, 2019).

Risks and benefits. The primary anticipated risk for participants was emotional distress,

which I made every effort to minimize by cautioning participants that some of the questions may

be upsetting, although the risk would be infrequent. I hold a clinical social work license and was

prepared to make referrals to participants for appropriate resources if needed; though, none were

required. While the risk was a reasonable speculation, I have not encountered significant

emotional distress discussing the injury during my tenure as either a practitioner or as a

researcher working with children and families impacted by burns; instead, conversations were

often described as cathartic in the absence of forums to share their feelings/experiences, even if

they were emotional. Moreover, the reconstruction of personal narratives in the wake of a trauma

is posited as a meaning-making process assimilating the experience into their life stories (Jirek,

2016). This was my observation during this research process. Although one of the participants was tearful during their interview, they denied wanting to stop. Furthermore, after the interview concluded I received an email communication that stated, "Thank you for letting [me] have the interview with you. I feel so much better letting things off the [*sic*] chest…I hope I can make a difference in someone else['s] life." For this particular participant, the only one visibly emotive, the risk of emotional distress was offset by the benefit they found in sharing their story.

Data Collection and Data Management

The previous section discussed sample selection, recruitment, ethical considerations, and risks and benefits. The following section will address how data was collected and managed.

Data collection. Riessman (1997) posits, **"**Personal narratives, in all their diversity, offer social scientists a window into personal experience, specifically human agency in the face of life events" (p. 157). Interviews provide the means for researchers and participants to engage a focused dialogue related to the personal narratives of study (Kramp, 2004). Therefore, I employed interviews as the primary source of data collection and asked adults to share their story of growing up the sibling of a child with a burn injury. Additional data included artifacts (Clandinin & Connelly, 2000; Riessman, 2008) and research memos (Birks, Chapman, & Francis, 2007; Merriam, 2002).

Interviews. Based on Riessman's (2002) definition, narratives are distinguished by ordering and sequence, as participants structure their stories temporally and spatially. By this very definition, they have a retrospective quality, with Gemignani (2014) positing, "[T]he past is constantly formed and reconstructed in its relations to the present and future…[where] these relations occur in unique historical and relational contexts" (p. 129). Therefore, "memory is made wholly neither in the past nor in the present but in the continual struggle between them"

(Olick, 2007, p. 29). Furthermore, when considering memory through the lens of narrative identity, McAdams (2018) asserted, "[N]arrative identity is not memory; it is the story told about memory" (p. 368). This ongoing dialogue of the past with the present and future therein positioned me, the research interviewer in the current moment, as an active participant in memory recollection, whereby accessing memory was a constructive act (Gemignani, 2014). By embracing a more intricate perspective on memory and remembering, rather than assuming recollections facilitate pure access to narratives, I focused on both the told and untold (i.e. remembered and forgotten), which advanced the constructive potential of the process (Gemignani, 2014).

The goal of narrative interviews, the most commonly employed method of data collection for narrative projects (Clandinin & Connelly, 2000; Riessman, 2008), is generating exhaustive accounts that require researchers' attention to detail and consideration of meaning or other associations linking stories together (Riessman, 2008). Although qualitative interviews can vary from unstructured, to semi-structured, to highly structured (Bogdan & Biklen, 2007), narrative interviews are more conversational than other methods since they center on storytelling (Riessman, 1993). When regarding the interview within the context of conversation, rules of everyday discourse apply, and generally include longer turns at talk from the participant to gain as much detail as possible (Riessman, 2008). Consequently, I was challenged to relinquish control and facilitated an environment where participants felt liberated to go on their own journey, while also fostering egalitarianism in the process (Riessman, 2008).

Riessman (2002) argues for less structure in interview instruments to ensure participants maintain a sense of control but encourages five to seven broad questions on the topic, as well as additional probes to enhance deeper thought and consideration. Therefore, an interview protocol

was used as a guide (see Appendix J). The specific wording of questions was less important than my emotional attentiveness, engagement, and reciprocity. I focused on the use of open-ended questions/statements designed to facilitate topics that allowed participants to construct answers they found meaningful. Examples included: "Tell me your story;" "Can you a remember a particular time when…?", "Tell me why that particular moment stands out?" (Riessman, 2008, p. 25). However, I also often asked clarifying probes or reframed parts of their narrative to help facilitate interpretation of their stories. I anticipated shifts in conversation/stories—one story leading to another—that required negotiating my attention to explore associations and meanings and the interconnectedness of multiple stories since Riessman (2008) advances narrative interviewing "necessitates following participants down *their* [emphasis in original] trails" (p. 24).

Stories were solicited by asking a stimulus question significant to the participant based on how our interaction began. The interviews began one of two ways. They were asked to explain the artifact—if they indicated they did in fact have one—they felt represented their relationship with their sibling either before, during or after the burn injury, regardless of whether they had the actual item with them at the time of the interview; or, I asked them to begin by sharing the incident that resulted in their sibling's injury. Again, this was determined from the natural flow of conversation. Four interviews began with an explanation of their artifact and three began by describing the burn injury incident. Although power differentials inevitably remained—argued by some as minimal—every effort was made for the participants, as narrators, to manage the agenda as opposed to trailing me as the researcher (Holloway & Freshwater, 2007). Although, as previously indicated, several of the participants had never discussed this topic before; so, some required the use of probing questions more than others. Therefore, narrative interviewing

facilitated an environment for storying participants to be active instruments in their reality as they defined their identities and stories, not passive recipients who had their experience shaped by others (Holloway & Freshwater, 2007).

Interviews were conducted both face to face for participants who were geographically accessible (n=3) and via the technology assisted technique of video conferencing (i.e. FaceTime) for participants who were not (n=4). Although face to face interviews have traditionally been the standard mode of data collection in narrative inquiry (Mealer & Jones, 2014), there is growing evidence that suggests Voice over Internet Protocol (VoIP) technology, such as Skype and FaceTime, are viable alternatives (Lo Iacono, Symonds, & Brown, 2016). Some of the advantages to VoIP technology include its ability to function synchronously and provide enhanced access to populations, while limiting geographic, time, and financial constraints (Janghorban, Roudsari, & Taghipour, 2014; Lo Iacono et al., 2016). However, inherent challenges include functional issues with the technology itself and the possibility for changes in establishing rapport or acuity to non-verbal cues (Janghorban et al., 2014; Lo Iacono et al., 2016). The same ethical considerations and procedures (i.e. informed consent and confidentiality) were engaged regardless of whether the interview was face to face or via VoIP.

Of the three interviews that occurred face to face, two of them transpired in conference rooms at fire stations proximal to each participant. The first interview conducted at a fire station was done so at the suggestion of the participant due to their familiarity with the fire department through participation in a fire service community program discussed in greater detail later. Time and geographical limitations resulted in my request to utilize a fire station conference room with an existing professional fire service relationship for another participant. The location was discussed in advance with the participant who verbalized agreement in the location being a

convenient and appropriate facility to record their interview based on the area and their work schedule. The third interview took place in a reserved conference room of a local public library convenient to the participant. The fire stations offered their conference rooms at no charge as a professional courtesy. The public library charged a nominal fee to secure a private room. Consideration was given to environmental factors and safeguarding privacy at the three different public locations, as well via FaceTime.

My experience with VoIP within the context of this study was positive. It facilitated an opportunity to engage with over half of my sample, which as previously noted was already challenging to locate; therefore, VoIP allowed expanded consideration in terms of participants physical location. I did not perceive a noticeable shift in establishing rapport or attention to non-verbal cues. This could be related to my comfort using VoIP in other aspects of my life. However, there were moments during each of the four FaceTime interviews that poor internet connection temporarily disrupted the flow of the dialogue, which was quickly resolved. Overall, this was a minor inconvenience, especially when considering it permitted an ease of access to participants in various geographic locations. Lastly, it is important to note that access to the internet was not a specific criterion of this study. If participants indicated they were unable to utilize the internet, alternative arrangements for a phone interview would have been made. Even so, it is important to acknowledge that participants ability to access technology—such as the internet and phones—pose inherent biases; yet, the limited knowledge and access to this particular population provided rationale to assume these biases and proceed with the intent of contributing to the knowledge base for continuing progress.

Participants were advised the interviews were anticipated to last between 60 to 90 minutes, although I remained open to the option of longer conversations pending the loquacity of

participants. The interviews took place between September 2017 and November 2018 and ranged in duration from 59 minutes to 105 minutes. Participants were also advised of the potential necessity for subsequent communication as it related to data collection and/or clarification and all consented if follow up was needed. Repeated dialogue with participants in their setting over time helped to ensure I was in tune with the nuances of interpretations through the conversation (Riessman, 2008), as well as address unanswered questions, or gaps, since qualitative analysis spirals from participants to analysis back to participants (Morse, 2015). A communication log was kept recording the exchanges of information between myself and participants. Lastly, at the start of the meeting, after addressing informed consent as noted above, but before commencing the interview, participants were asked to complete a questionnaire (see Appendix K) that gathered general demographic information and timelines related to the incident. I was prepared to assist participants if they indicated any reading or writing comprehension issues, but none specified a need.

    Artifacts. Materials such as photographs, memory boxes, and/or other items with personal/family/social importance, referred to as artifacts, can also aid in the construction and interpretation of narratives (Clandinin & Connelly, 2000) and are not new to social science research (Riessman, 2008). However, it was important that I remained mindful the artifacts were initially created via the lens of whoever authored and/or archived the materials (Riessman, 2008) and were being described by the participant and subsequently interpreted by me as the researcher. According to Clandinin and Connelly (2000), "It is these artifacts, collected in our lives that provide a rich source of memories" (p. 114). Therefore, although interviews were the primary source of data collection, participants were asked to bring an artifact to the interview they felt symbolized their sibling relationship, either before, during or after the burn injury. They

were further advised that the items would be used to help guide our conversation, as well as provide an additional source of data. Four of the participants furnished an actual artifact, two described the artifact they wanted to provide but were unable to locate, and one declined. Of the four participants that supplied artifacts, three sent images of their artifact to me electronically. Two provided their artifacts in advance of the interview electronically and one provided electronically after the interview, though they still discussed and described it during the interview. For the one participant who delivered the item at the face to face interview, images were taken following the informed consent process and completion of the questionnaire. The most frequently provided or discussed artifacts were photographs (n=4). The other two items were an electronic device (n=1) and a school project (n=1).

Research memos. Finally, research memos functioned as my personal narrative of the research process as it unfolded to ensure accuracy of chronological records, as well as my own reflective thoughts, which evolved over the process (Merriam, 2002). Memos are employed in qualitative research to "assist the researcher in making conceptual leaps from raw data to those abstractions that explain research phenomena in the context in which is it examined" (Birks et al., 2007, p. 68). Specifically, I employed the use of a Microsoft Excel (Version 16.24) workbook to manage recruitment details, professional transcription service dates and costs, participant information, and a communication log. I also used Microsoft Word (Version 16.24) to create individual participant memos that documented my reflections following each interview. Furthermore, I utilized ATLAS.ti (Version 8.3.1) to facilitate reflexivity in addition to analysis (Woods, Macklin, & Lewis, 2016). Specifically, I created memos for each participant with reflections following the initial coding of their transcripts. I also maintained memos that recorded

emergent concepts, iterations of ways to consider the presentation of findings, and critical reasoning and discussion thoughts.

Trauma and qualitative research data collection. Researchers proxy as the research instrument in qualitative methodology. Participants, particularly in narrative inquiry, often reveal thoughts or stories they may otherwise not share since there is a greater likelihood of disclosing private thoughts in stories versus responding to questions (Holloway & Freshwater, 2007). For many, myself included, there is a sense that positivistic approaches are not appropriate in capturing the humanness of an experience, particularly trauma (Connolly & Reilly, 2007). Consequently, inherent risks involving research into the stories of trauma were critical to remember, for both participants (Riessman, 2008) and myself in the role of researcher (Connolly & Reilly, 2007; Kiyimba & O'Reilly, 2016). Although the impact of vicarious trauma is not well explored from the lens of qualitative researchers conducting these types of sensitive inquiries (Taylor, Bradbury-Jones, Breckenridge, Jones, & Herber, 2016; Warr, 2004), growing literature advocating the welfare of researchers during data collection related to trauma, including professional transcriptionists (Kiyimba & O'Reilly, 2016; Rager, 2005), is encouraging.

Connolly (2007) highlighted her own experience conducting interviews acknowledging trauma "becomes contagious between the researcher and the researched individual" (p.534). Four specific issues were highlighted, including: the researcher's fluid identities; reflexivity as a both an essential and critical exercise; research and participant reciprocity matters; and observed personal stresses related to the traumatic inquiry (Connolly & Reilly, 2007). Therefore, attentiveness to my own feelings and reactions were critical to protect the integrity of the research, as well as my personal wellbeing. Strategies to inoculate, as much as practically possible, included: memoing, as previously emphasized; regular debriefing with a colleague; and

spacing interviews (Connolly & Reilly, 2007). Debriefing with a colleague was critical not just within the context of the routine research experiences, but with added focus on the challenges related to my fluctuating identities and disarming the emotionally charged data contexts (Connolly & Reilly, 2007). I also attempted to manage the accumulation of all noted above by spacing interviews. With the exception of two interviews that occurred on back to back days, the remaining interviews were spaced out over several months. All that said, as noted by Holloway and Freshwater (2007), "Suffering is open-ended, and the experience of suffering is suited to the narrative style and biographical work. Understanding can best be achieved through listening to other people's stories" (p. 710). It was just critical I remained vigilant to my own prospect of distress in the process, which was further compounded by the personal circumstances noted earlier.

Data management. Interviews were recorded digitally on three different devices and artifacts were either sent electronically or captured via a photographic image. Interviews were transcribed professionally in three waves: interviews 1-4, 5-6, and 7. Once the transcripts were received from the professional transcription service, they were thoroughly reviewed and sanitized via the assistance of Express Scribe Transcription Software (v. 7.03). According to Riessman (1993), "Taping and transcribing are absolutely essential to narrative analysis" (p. 56). Although I did not personally transcribe the interviews myself, I recognize the value and importance of becoming closer to the stories, which was achieved via the reviewing and sanitization process to enhance the accuracy of the data after professional transcription. Audio files and transcripts were stored in password protected cloud drives (e.g. Dropbox and Google Drive), as well as my password protected computers. All information remained confidential, with pseudonyms assigned to each participant and employed in the transcription. Pseudonyms for

participants were selected by going to a baby name website generator

(www.babynamewizard.com/voyager). Specifically, an ordered letter from the participant's last

name was used as first letter in their pseudonym. The names were chosen based on each

participant's age and names that were popular during the decade of their birth according to that

website. A similar method was employed for the injured siblings. Transcripts were also later

moved into ATLAS.ti for ongoing analysis—discussed in greater detail next—and the QDAS

was stored the same as the transcripts noted earlier (i.e. password protected cloud drives and

computers).

Data Analysis

Compared to other forms of qualitative research there is no procedural standard for

"doing narrative analysis" (Riessman, 1993, p. 54). Analysis can done in a myriad of ways, such

as: thematic—analyzing *what* was said or themes told by the participant, rather than how it was

constructed; structural—in addition to content, meaning shifts from the told to telling the story,

emphasizing *how* it was told, including language and form; dialogic/performance—drawing from

the first two methods it also investigates *who* the story is directed towards, *when*, and *why* with

close contextual readings for expanded interpretation; and visual—integrating words and images

(e.g. photos, paintings, collage, videos) to either tell the story *with* or *about* the images

(Riessman, 2008).

Of the four analysis methods, thematic is most like grounded theory and interpretative

phenomenological analysis qualitative methods (Riessman, 2008). However, a key distinction

related to coding between grounded theory and narrative inquiry is narrative's preservation of

story sequencing for interpretative purposes versus thematic coding segments, in addition to

narrative's case-centered commitment to analysis versus theorizing across cases (Riessman,

2008). van Manen (1990) states, "[L]ived-experience descriptions can be found in a multitude of expressions or forms…[including] in daily accounts or stories" (p. 92). These lived experience descriptions provide foundations for uncovering thematic aspects of the described phenomenon, which can be explored in three different approaches; holistic, selective, or detailed (van Manen, 1990). Within the context of this study, data is represented as case-centered individual stories, as well as thematically across all accounts.

Fraser (2004) posited an outline of intersecting and non-sequenced phases to facilitate the narrative analysis process that includes: (a) hearing stories and experiencing emotions reflected during and after the interview, as well as journaling reactions for awareness of how they impact subsequent interpretations; (b) transcribing the interviews, which facilitates immersion when done by the researchers, is also recognized as more than just what was said, since researchers make decisions along the way based on their unique perspectives (Riessman, 2008); (c) interpreting transcripts to note types and directions, in addition to contradictions, of the stories; (d) scanning narratives across different domains of experience, including intrapersonal, interpersonal, cultural, and structural aspects; (e) engaging prevalent discourse attentively, such as "the aftermath," "recovery," and "rebuilding," which according to Herman and Plummer are examples of metaphors in trauma narratives suggesting the interpretative framework of the story (as cited in Fraser, 2004, p. 193); (f) focusing specific attention to similarities and differences across transcripts, which likely occurs concurrent to the other phases; and lastly (g) pulling together material to construct narratives, or stories, as the representation of findings/experiences. These narratives are also now the researchers as the storytellers who reflect the plurality of truths (Clandinin, 2013; Leggo, 2004; Riessman, 1993, 2008).

Riessman (2008) acknowledges that individuals looking for a guide or "set of rules" (p. 53) for doing thematic analysis in narrative inquiry will be disappointed. Therefore, for the purposes of this study, I utilized Fraser's (2004) guidelines in tandem with Riessman's (2008) thematic analysis, the most common narrative analysis method, as well as the most approachable and engaging for applied settings, where my attention focused on *what* was said. Specifically, analysis queried the following four issues regarding individual stories: how narrative was employed; how data were represented, with particular attention on language and form; the focus or unit of analysis; and consideration to micro and macro contexts (Riessman, 2008).

As noted, the transcripts were subsequently moved into the QDAS ATLAS.ti (Version 8.3.1) for assistance in the organization and interpretation of data after they were reviewed and sanitized. Although the use of QDAS has been debated in the qualitative paradigm (Bassett, 2004; Lu & Shulman, 2008), proponents such as Konopásek (2008) argue its utility in allowing, "researchers to *think in a visible way* [emphasis in original]. Visualised [*sic*] thoughts or mental operations can easily be stored, recollected, classified, linked, filtered out in great numbers … and made meaningful *in sum* [emphasis in original]" (section 7, para. 2). I employed van Manen's (1990) selective or highlight approach with the transcripts within ATLAS.ti where during this selective phase of reading, through an iterative approach, I read the text multiple times and considered what phrases or statements seemed essential or informative regarding the experience of growing up the uninjured sibling. Phrases/Quotes that appeared essential were then selected/highlighted within the QDAS program and given a code. After engaging this process of initial coding across all seven transcripts, I then went back to each individual transcript and wrote detailed accounts of their unique experience, paying particular attention to the chronology for story sequencing and utilizing verbatim quotations as much as possible. This process allowed

me to further familiarize myself with the data by reading and re-reading the texts. Thus, this repetitive process advanced distilling the codes across participant transcripts from the first round of coding.

Though the phrases/quotes were initially given a code prior to writing individual accounts, there was ongoing analysis of the preliminary codes, as well as how they were grouped together based on their similarities. After each participant's individual account was written, the single codes, as well as the larger grouping of codes were refined and converged into overarching themes that linked back to the research questions. According to Braun and Clark (2006), "A theme captures something important about the data in relation to the research question, and represents some level of *patterned* [emphasis in original] response or meaning within a data set" (p. 82). Though there is not a standard for the number of participants to contribute to a theme (Braun & Clarke, 2006), I followed the research of Tasker and Stonebridge (2016)—exploring the needs of seven adolescent siblings of children with cancer—and considered an overarching theme when there were at least four of the seven participants with contributing data.

An example from the data will be provided to illustrate how codes were grouped and later collated into a theme. The initial code "caregiver" was eventually grouped together with the codes of "protector," "questions and stares," "differential treatment," and "emotional embargo." This grouping of codes that seemed to fit together were eventually folded into the overarching theme "altered interactions and ambivalent roles." Some of the codes, for example, "protector," have sub-categories such as "verbal," "physical," or "withholding feelings." There were a few codes that had only one participant with contributing data, yet it was the context of the data that prevailed (Braun & Clarke, 2006). This was the case with the "emotional embargo" code that

was interpreted as part of the "altered interactions and ambivalent roles" theme. One participant had numerous examples that supported this code, which I reasoned relevant for consideration within the overarching theme as supporting data, with potential implications to consider in future research.

Again, a theme was considered so long as it had at least four of the seven participants contribute to the overarching theme, not the codes (or sub-themes) that organized into the overarching theme. The first four themes were inductive, or data-driven (Braun & Clarke, 2006), and attended to research questions one and three. This inductive process of coding did not attempt to have data fit an established coding structure (Braun & Clarke, 2006). However, the second research question regarding what participants' narratives revealed about how their identities were shaped employed a theoretical thematic analysis (Braun & Clarke, 2006) based on the earlier work of Lilgendahl and McAdams (2011) and McLean and Thorne (2003) within the context of self-growth, which provided less emphasis on rich description and more detailed analysis (Braun & Clarke, 2006).

The selected phrases/quotes, which aided in the formation of individual accounts, as well as elucidating themes across participant stories and differences that made their narratives unique, were also relevant in conceptualizing as a metastory (Riessman, 1993), or hybrid story. Therefore, data representation included a detailed story for each research participant—along with brief artifact descriptions and images—as well as one overall metastory, and overarching themes. That said, Riessman (1993, 2008) outlines two critical assumptions related to the production of texts that are important to consider: first, narratives are not discovered, rather researchers participate in their creation; second, these narratives are not the "real thing" but participants' representation of them.

Strategies to Assess Data Quality

What qualifies as "good" qualitative research is debated in the literature (Connelly & Clandinin, 1990; Freeman et al., 2007; Lincoln & Guba, 1986; Merriam, 2009; Riessman, 2008). According to Merriam (2002), "'Good' is of course a relative term…what people usually mean…is whether the study was conducted in a rigorous, systematic, and ethical manner, such that the results can be trusted" (p. 24). Riessman (2008) also refutes the notion of standard criteria stating, "It can paralyze and, in my view, simplify what are complex validation and ethical issues all investigators face" (p. 185). Instead Riessman (2008) argues the levels of validity for narrative research—the story told by the research participant and the story told by the researcher—should be evaluated within the context of the frameworks that structure the study. She proposes four "facets of validity" (Riessman, 2008, p. 185) as means to further conceptualize quality.

The first facet, historical truth and correspondence, recognizes that "truth" is contingent upon a researcher's orientation; however, approaches to analysis should be clear, including documenting sources—primary or secondary—and inviting the audience on the journey to evaluate and interpret claims (Riessman, 2008). Therefore, working from a social constructionist perspective, understanding meaning for participants is the goal, not verification of facts, as in realist epistemology. As stated by Bruner (1991), "[V]erificationist criteria have limited applicability where human intentional states are concerned" (p. 18). So, although my concerns were not with *the* truth—since narrative is not concerned with a factual record of what truly happened, but a constructed account of the experience—I provided cumulative evidence, reviewed above, of my interpretative account "storying the stories" (Riessman, 2008, p. 188).

I encouraged participant engagement by member checking to ensure the accuracy of my interpretation (Lincoln & Guba, 1986; Merriam, 2002). Each participant was emailed their detailed story and asked to review it carefully for any revisions or comments. Additionally, in that same email, participants were provided a link to a Qualtrics survey where they were asked to review the five themes that appeared prevalent across all interviews to the experience of growing up with a sibling who experienced a burn injury in childhood. The following instructions were provided within the actual survey,

> After analyzing data from all participants, 5 themes (or patterns) appeared prevalent to the experience of growing up with a sibling who experienced a burn injury in childhood. Keep in mind each person's story is unique and the themes are not meant to reduce or dilute the nuances of your experience. Before presenting these findings in much greater detail it is important to gather direct feedback from you. The 5 themes are listed below, including a brief description, along with several supporting quotes from the collective data (so they will not all be specifically yours). Please review each theme carefully and select either "Agree" or "Disagree" to indicate if you feel the overall theme accurately represents your experience. There is a text field for additional thoughts/comments but is not required. This should only take 5-10 minutes of your time. Thank you again for participating in the study!

Participants were asked to respond within 10 days and advised that if no response was received it would be assumed that they supported the accuracy of the findings. All seven participants responded by the deadline and endorsed the five themes, as well as their stories. Two participants noted small revisions to their stories, which included clarifications of quotes (n=2) and a change in relationship status (n=1). Prior to sending this email link out to participants, I had colleagues

both in and out of the social work field review the wording and formatting for readability and ease of use. Lastly, I engaged peer review and discussed the data and my interpretations with a colleague familiar with the research area to assess whether the findings were plausible, which concurrently provided a mechanism to debrief and discuss developing hypotheses (Lincoln & Guba, 1986; Merriam, 2002).

Next, cohesion, persuasion, and presentation challenge notions such as: whether the story hangs together; if inconsistencies or gaps are identifiable; and if the interpreted version persuades the audience (Riessman, 2008). Persuasion is strengthened by precision when using verbatim quotes from detailed transcripts, maintaining an audit trail, and engaging reflexivity (Riessman, 2008). Therefore, I employed the use of an audit trail for methodological awareness, recording in detail my data collection methods, decision-making, and inferences, as well as critical reflections about the research process, including self-care and my personal responses related to fluidity of roles and stress/compassion reactions previously indicated (Connolly & Reilly, 2007; Lincoln & Guba, 1986; Merriam, 2002; Rager, 2005). I safeguarded transferability with thick description, providing detailed information about both the participants as well as the stories (Creswell, 2013; Lincoln & Guba, 1986). Moreover, I included the use of negative cases—or instances that did not fit the pattern of the theme (Patton, 1999)—and considered alternative interpretations that Riessman (2008) suggests strengthens persuasiveness. Finally, I believe my 19-year history of work in the burn community provides reasonable consideration for prolonged engagement with the population of interest (Lincoln & Guba, 1986).

The third facet of validity, pragmatic use, considers practical implications of the work as a basis for building knowledge; in other words, will my work become the basis for other work (Riessman, 2008)? Although time will determine the worth of this study within the greater

academic audience, I do envision it serving as a springboard for other research, in addition to substantive—arguably demonstrating trustworthiness (Riessman, 2008)—and theoretical implications, which will be discussed in the final chapter. Narrative research is a type of case-centered inquiry, leading to contentious debates regarding generalizability (Gilbert, 2002; Riessman, 1993, 2008); yet Flyvbjerg (2006) posits five arguments for generalizability: case studies generate context dependent knowledge; cautiously chosen cases employed with reflexivity spawn advancements in the scientific knowledge base; inquiring into extreme or anomalous cases is frequently required to extend theory; daily circumstances can be understood in depth versus in breadth; and case studies promote the focus of attention on story details.

Finally, political and ethical use begs the question: does this study contribute to social change and/or foster social justice (Riessman, 2008)? According to Jirek (2016),

> As a discipline that values social justice, groups that are marginalized, and voices that are stifled or disregarded by society, it is of paramount importance that social workers pay attention to the narrative gaps and silences, the unpopular narratives, and the narratives of the disenfranchised. (p. 19)

It is central to my thinking that elucidating the stories of uninjured siblings will promote social change through the likely development/enhancement of programs/services, as well as foster social justice through the arrant act of providing a forum for the stories to be told and disseminated. At a minimum, it is my hope this research encourages dialogue and an acknowledgement that uninjured siblings were impacted by the burn trauma, therein establishing a formidable argument to explore the dynamics within the context of family/caregivers further.

Limitations

As previously detailed, research exploring the experiences of uninjured siblings within the context of a burn injury is minimal. As such, this study presented uninjured adult siblings taking a retrospective approach an opportunity to share their realities and interpretations in their own words and afforded an opportunity for them to feel empowered as the expert on the subject and have their experience acknowledged. Although narrative inquiry's strength lies in its ability to gain an in-depth understanding of individual lives told in their own words, though filtered through the researcher (Clandinin, 2013; Riessman, 2008), there are methodological limitations to consider. Primarily, there were decisions made around analysis and interpretation of data, though attempts were made to enhance the credibility and quality of the study and presentation of findings, including member checking (Lincoln & Guba, 1986; Merriam, 2002), use of verbatim quotes, maintaining an audit trail, and providing negative cases (Riessman, 2008). I also engaged peer review with a colleague familiar with the burn community to discuss the plausibility of findings (Lincoln & Guba, 1986; Merriam, 2002). Furthermore, the small sample size employed with narrative inquiry (Gilbert, 2002; Riessman, 2002) makes generalizability a controversial construct (Gilbert, 2002; Riessman, 1993, 2008); however, Flyvberg (2006) argues the utility in knowledge acquisition from a single case. Furthermore, this particular investigation was about elucidating knowledge yet to be explored or understood, therein sustaining the argument for the appropriateness of this particular qualitative approach.

Though recruitment of participants was anticipated to be difficult, it proved more challenging than expected; yet, this also strengthens the argument for how isolating the experience is for uninjured siblings. As a result of recruitment challenges, the sample lacks racial and ethnic diversity. However, the sample does provide geographic diversity based on

participants' location around the United States and Canada and a representative number of males and females when considering both uninjured and injured siblings. If programs and services within the context of the burn community do not acknowledge the implications for uninjured siblings inclusion, identity, and resource acquisition that were elucidated by this study, accessing them for further understanding will likely remain a challenge and sustain missed opportunities to intervene on both the individual and family level.

It is also critical to remain mindful that many of the participants were from families who experienced a number of stressors (e.g. divorce, substance use, mental illness, maternal abandonment) in addition to their siblings burn injury, which sometimes occurred in parallel (Steger & Park, 2012). This study was not meant to make suggestions about the causal relationship of events; however, instead it was intended to highlight uninjured siblings individual accounts and themes across stories, while gleaning ways they felt—at the time of the interview—the experience of growing up with a sibling who experienced a burn injury in childhood impacted their identity, recognizing the same event can produce varied meanings for the exact same person at different points in time (Josselson, 2009). Yet, their narratives have compelling implications for the necessity to intervene and provide resources/support to them that will be discussed in the final chapter.

Social constructionism (Lincoln & Guba, 2000; Schwandt, 2000; Witkin, 2012) and narrative identity (McAdams, 2018; McAdams & McLean, 2013) provided meaningful frameworks to guide the study. Yet, those seeking one truth will challenge the utility of the social constructionist framework that posits multiple equally valid realities (Lincoln & Guba, 1986; Schwandt, 2000). Though some may perceive this as a limitation, the purpose of the study was to understand the lived experience—posited in detailed stories and themes—from uninjured

siblings' perspectives through co-construction with me as the researcher (T. Andrews, 2012; Gergen, 1985; Guba & Lincoln, 1994) not claim one single experiential truth. Furthermore, narrative identity's absence of reductionist theories—argued as both a strength and weakness— also provides a more descriptive account of identity versus explanatory (J. A. Singer, 2004).

Finally, limitations inherent in my role as the research instrument are also worth considering. As detailed in my subjectivity story, I engaged the study with both professional and personal influences that were acknowledged to provide consideration for my analysis and interpretation in an effort to minimize the potential for perceived manipulation (Clandinin & Connelly, 2000). Additionally, the subject matter was emotive with inherent risks to my personal well-being (Connolly & Reilly, 2007), which was further compounded by my mother's illness and subsequent passing. Consequently, it heightened the importance for me to identify when I needed to give pause for my own welfare (Connolly & Reilly, 2007; Kiyimba & O'Reilly, 2016; Rager, 2005); yet, as also indicated, I also found the study to be a powerful way to work through some of my own grief and mean-making (Jirek, 2016).

Chapter Summary

This chapter provided an overview of the methodology used to guide this study. Specifically, it addressed the following areas: 1) Subjectivity Statement; 2) Research Design; 3) Methodological and Theoretical Paradigms and Frameworks; 4) Methods of Data Collection and Analysis; 5) Strategies to Assess Data Quality; and 6) Limitations. The following two chapters will present the findings. Chapter 4 offers as a detailed story for each research participant—along with brief artifact descriptions and images—as well as one overall metastory. Chapter 5 presents the overarching themes that were identified across individual experiences and supporting quotes.

CHAPTER 4

RESEARCH FINDINGS—STORIES

Introduction

This chapter functions as one of two analysis chapters. Chapter 4 will begin with a brief overview of participants, including their demographic information. Next, detailed stories of the participants experience growing up as the uninjured sibling in childhood are offered. The stories are accepted as participants' truth or reality, based on the meanings they made at the time of this study (Riessman, 1993, 2008). The detailed stories are told through the lens of the participants as closely as possible. Additionally, images of artifacts participants were asked to provide, which they felt represented their relationship with their sibling either before, during or after the burn injury, are recounted following each story, along with a brief explanation. Finally, the chapter concludes with a metastory (Riessman, 1993), or hybrid story, as a representation of all participant experiences. Four of the seven participants directly reported they had never been asked about what the experience was like for them. It was truly an honor to be their first audience and afforded the opportunity to examine each of their personal contributions for knowledge acquisition—substantive and theoretical—as well as outline implications for program development/enhancement, both in social work practice and beyond.

Participant Information

The seven participants all identified as white and ranged in age from 20 to 57 years old. Four of the participants identified as female and three identified as male. All reported completing at least high school. Additionally, one reported attending trade school, one reported "some

college," and three reported attending college. At the time of the interview, three reported being single, two married, and two in a relationship. One participant left their response blank on the demographic sheet, but during the interview indicated being in a relationship and during member checking stated they were currently single. There was a total of eight injured siblings between the seven participants. Five of the injured siblings were females and three were males. One participant had two siblings injured in the same incident. The siblings ranged in age from 0 to 13 years old at the time of the burn injury incident. One participant was not born at the time of their sibling's injury. When considering the TBSA or the location of the injury, as previously discussed criteria to assess burn injuries, seven out of the eight siblings injured experienced burns that are classified as either major burn injuries or injuries that should be treated at specialized burn centers. Additional demographic information can be located in Tables 1 and 2 for both participants and their injured siblings, respectively.

<div align="center">**Individual Stories and Artifacts**</div>

Individual stories for all seven participants with assigned pseudonyms are presented below in the order of their interview. After reviewing and sanitizing the transcripts, I went through each of the interviews and initially coded for patterns or themes, which will be discussed in Chapter 5. Next, I went back to each transcript and wrote individual detailed accounts of their experience, with focus on chronology for story sequencing (Riessman, 2008) and also utilizing verbatim quotes (Riessman, 2008) to promote authenticity in the depiction of participant's stories as much as possible. Direct quotes from participants are in italics. Most participants were not accustomed to sharing their experience, so stories were frequently temporally disordered and tangential, which required attention to detail when drafting their unique accounts; though, enduring a lengthy and meticulous process is not uncommon within the context of narrative

research (Gilbert, 2002; Riessman, 1993, 2002). Following each story are brief descriptions of their artifact(s), if one was provided.

Alyssa

It was a "*normal*" Sunday morning in September—two months after a family trip to Disney World—for 3-year-old identical twins Alyssa and Tiffany and their 7-year-old brother Tyler. At 10 a.m. it was already hot and humid—the twins wore just their diapers and shorts. Their dad was in the yard cutting the grass. Meanwhile the kids were around the house, each doing their own thing—Alyssa napping, Tyler doing "*whatever boys do*", and Tiffany playing down in the basement. Unbeknownst to the family, Tiffany picked up a gas can from outside— typically stored in a shed out behind the house—and brought it into the basement setting it down next to the hot water heater, which was also near the washer and dryer.

The minutes that followed—for Alyssa her, "*Where were you when the world stopped turning?*" moment—are something seared into her memory like Tiffany's 75% third degree burns that cover her arms, legs, feet, hands and torso. The gas can—now sitting next to the water heater—caused the air to ignite. Alyssa recalls, "*Tiffany wasn't actually touched by the flames, but she was in a ring of fire. So she was, in a sense, baked and of course that's a joke [with] all of us.*" Their dad raced to the basement after Tiffany and rescued her from the "ring of fire"— recognized as a miracle for a man not trained in firefighting or search and rescue—finding her between a table saw and a melted bicycle. During the valiant recovery of his daughter he sustained first and second-degree burns, as well as scarring on his lungs. The scarring on his skin is no longer visible, but the scarring on his lung tissue remains, resulting in ongoing medical complications, including lung surgery a few years ago.

While Tiffany's dad was delivering her from the basement, Tyler grabbed Alyssa from the upstairs part of the house to get them outside—before they could look for Tiffany—where they waited at their safety spot. Alyssa remembers the family had practiced this process many times but were surprised the day arrived that forced them to utilize their skills. Alyssa says,

> *I remember watching her being taken from my dad's arms, watching her skin basically slop off onto his arm, and the smell of burning flesh at three years old makes you want to crinkle your nose and scream. That's what we did, we were screaming.*

She remembers how the family dog attempted to knock Tiffany in her head to keep her out of shock. Alyssa's struggles to grab and get closer to Tiffany—who she desperately wants to be with—were suppressed by another firefighter on scene.

Alyssa's 3-year-old brain tried to sort out why her unconscious sister was being placed in an ambulance. She remembers Tiffany came to long enough to scream out in the most unimaginable pitch—one that haunts Alyssa—as firefighters poured water over her body laid out on the stretcher. This was a defining moment when everything in her life changed, "*[Y]our whole world flips around.*" Alyssa went from being inseparable with her twin in their close-knit family, to months of disconnection from both her family and her home, which had succumbed to the fire and left only a brick skeleton. Alyssa inventoried her thoughts following the immediate aftermath that morning and details,

> *[I]t's kind of like your world is at a standstill. You're really not sure what direction to move, especially, my parents went with Tiffany, I'm stuck with a neighbor. You don't know what to do. You want to go to your house and get your stuff, but your stuff is gone. You're told that everything is gone, but you're just still like, "Okay, what do I know?" Being so young you don't really understand. You know fire destroys things but you don't*

know to what extent. You know when you touch the stove, it hurts, so how much pain is

Tiffany actually in if she was just stuck in there? You have a lot of questions, but not sure

how to ask because you're the kid.

Seventeen years later, Alyssa upholds that this remains the moment when her world stopped turning.

Her dad's injuries resulted in a short hospitalization, leaving Alyssa's mother to stay with Tiffany at the hospital until her father's release. Due to the gravity of Tiffany's injuries, she was life-flighted to a metropolitan burn center, which grounded Air Force One carrying President Clinton to a press conference—a point of both pride and humor for Tiffany. She initially underwent 14 to 15 hours of surgery for the doctors to assess the extent of her injury and clean the wounds. Tiffany's medical care was provided by local burn center; however, Alyssa overheard talk of her being transferred to a facility in another state and "*freaked out,*" confused by how/why her sister would be in another state. When asked how Alyssa received her subsequent communication about Tiffany's progress she replies,

[N]o one really wanted to talk to a three-year-old, so I was just piecing together

information. Whoever had me at the time, they're always talking on the phone to mom,

calling for updates and I'd pretend to be asleep. They'd be sitting there just talking all the

way about it and that's usually how I found out. They talked to my brother a little bit

more about it and he'd make sure to tell me about it.

The night of the fire Alyssa stayed at her aunt's house and cites waking up on her couch alongside any salvageable belongings from their home, noting most things were ruined from either the fire itself or from damages during the cleaning/restoration process. However, in the days and weeks that followed she remembers a sense of community. Alyssa brags on her

hometown, stating, "*I had nothing and then I had a whole bunch of something.*" This extended into the hospital setting as well, where she recollects Tiffany's frightening twenty percent chance of survival and the medical community who celebrated every victory.

The emotional first visit with her sister came Tuesday, two days after the injury, in between surgeries. She recalls the brief encounter,

> [*T*]*he first time I saw her, everybody was boo-hooing. Everybody still talks about this moment. They were wheeling her by and all she wanted to do was hold my hand and they wouldn't let me touch her and she screams, "Sissy" ...and so did I. Even doctors, nurses, everybody, they said it was the worst thing they've probably ever seen. Just the fact that I couldn't even touch her was probably the worst part.*

She can still envision the hospital room with her mother's belongings on the couch where she "*camped out pretty much,*" and begging her mom to let her stay. Alyssa yielded to her mother's explanation that she was too young and left with her recently discharged father to the gratis hotel room, reiterating, "*The community really took care of us.*" Despite the insurance company's suggestion to find a new home, their father worked "*day and night*" following his hospital discharge and rebuilt their home in three months; however, they have since moved numerous times noting it "*was kind of weighing us down.*"

During Tiffany's hospitalization—with her mother at the hospital and her dad working, as well as rebuilding their home and visiting the hospital—Alyssa recalls the stress of "*bouncing around*" from relatives to friends and back to relatives, trying to adjust to an augmented routine where, "*Sometimes you're with people you don't know, they're not the nicest people, they're nothing like your parents.*" Alyssa tried to process the separation from her family and grief associated with losing her home, but often suffered in silence disclosing,

You want to tell people you're hurting too but you're made to feel like you're not hurt. You know, I don't have any physical scars so I'm okay, but your whole world flipped upside down. And even though you're young they're like, "She's not going to remember it." You still remember the little details, the traumatizing details I want to say. That's pretty much what it boils down to, is just being kinda kicked to the side.

Alyssa perceived her twin sister—her "*whole world*"—disappeared and the pains that followed included a sense of loss for her sister. Moreover, she wrestled with the shattered notions of her own identity expressing,

[T]he next thing you know you're taking care of them, your protector, you're beating up kids at school that want to say something about her. It changes you. I was supposed to be, who knows, I was supposed to be the nice girl, pretty in dresses, but I grew up tough, grew a tough skin, fought a bunch of kids in school, stayed in trouble, but in my head it wasn't trouble, it was protecting.

During the first couple of weeks following the incident, as well as other times supervision was needed that family could not provide, Tyler stayed with a friend up the road from their house. The family was unable to care for Alyssa, which she understands to be because there were three other teenage boys and they did not think it would be a good fit for a 3-year-old girl. Consequently, Alyssa stayed with either her maternal grandmother or her aunt; however, there was another woman—a friend of her grandmother's—and she discloses,

[W]e don't really talk about her…She wasn't very nice and I was a kid that was just kind of extra in her house…She would stick me in a corner, she used to beat me, she beat me when I spilled milk one time.

Alyssa stayed with this woman for a couple of weeks and during visits to see her grandmother—who worked for the Sheriff's Department—she was questioned about bruising that others noticed on her, which coincided with changes her parents began to observe. Once the gravity of the situation was understood, Alyssa's parents filed a report and the women was subsequently arrested for child abuse. Moving forward she stayed with either other family members or her parents at the hospital. In an effort to protect Tiffany she admits,

> [W]e just kind of don't think about it, talk about it, it's kind of like an unspoken subject in the house, mainly because we keep it from Tiffany. She blames herself for the fire and we know it. I don't want her to blame herself for something that's history.

Alyssa acknowledges Tiffany knows she was "*passed around*" while she was hospitalized and has "*suspicions because people have said stuff and she would ask questions,*" but to denies any further discussion about the situation.

Aside from the incident with the woman above, Alyssa chronicles the family being investigated by child protective services for a possible child cruelty case due to a write up in the local paper that suggested the fire and her sister's injury were her dad's fault. If there is one thing Alyssa asserts with conviction it is that the fire was "*just an accident,*" vehemently exonerating both her sister and her father of blame. Rather, Alyssa speaks fondly of her parents and their support proclaiming, "*My parents were awesome.*" She also acknowledges the relationship she maintains with Tiffany as something more than the "*twin thing,*" boasting,

> [I]f I really needed someone, [Tiffany's] the person that would be there, because like I said, we're always there to [sic] each other. We're always that person, and she's the first person I call with anything. And I have a fiancé. I'm supposed to be calling him, but Tiffany's still my number one.

Tiffany remained in the hospital for 3 months—much better than the 6 months to a year the doctors predicted—before she was discharged; though, her care still required multiple follow up appointments during the week. It was a time of transition for the entire family who were still coping with the loss of their home and belongings—a period Alyssa refers to as the "*numbing stage*"—that now included the loss of mobility outside the home due to Tiffany's injuries. Nonetheless, Alyssa notes having Tiffany "*sleeping at home made it a lot better.*" Yet,

> [I]t was a lot of adjusting. It was like bringing a newborn home. Tiffany's basically growing new skin back, it hurts. Every time you moved her, she screamed. I had my best friend back, but I couldn't do anything with her. I was 3 years old wrapping a bandage. When you have to change bandages, put more Silvadene on, those screams would haunt you in your sleep.

Although Alyssa acknowledges she may not have performed all aspects of Tiffany's care, she remembers being there and holding her hand during the dressing changes, which resulted in "*basically ripping clean flesh off.*" While elated to have her sister home, she admits feeling angry and struggling to adapt, which she exhibited by "*show[ing] out.*" This behavior was often followed up with reminders from family/relatives that she "*could have it worse.*" As a result, Alyssa states, "*[Y]ou just kind of build your own little bubble and you stay in it.*"

Alyssa upholds a critical piece of her experience that remains unacknowledged are her nightmares. At 20 years old, she still endures distressing dreams of her house burning down or others where she is unable to find her sister in the burning house. She describes,

> Everything starts flushing [sic] back, even stuff you don't remember. You didn't think you remembered, it just kind of unlocks a certain part of your brain…and there's nothing you can do in it.

Furthermore, she is now forced to face the realization,

> *You're not invincible to it. We were the perfect family. Mom had twin girls, we had a brother, we'd tease him, fight all the time, we had a beautiful house. It was that brick house with the white picket fence…Everything changes, you're scared of everything. Anything could happen. You're not really paranoid, more prepared, but I feel like a person shouldn't have to prepare for that.*

And then there's the guilt she grapples with most days for not being the one who was injured. Still she maintains,

> *I thought about everything that I went through just watching Tiffany and sometimes think she got out easy… She didn't have to watch me go through it. She didn't have to feel the pain, but not have the pain acknowledged. Not discouraging her scars or anything, that was the worst pain anybody can have is being burned alive, but sitting from the sidelines, not being able to do anything, that's about as equal. The only thing you can do is take care of them, but they're still hurting. You can give them pain medicines; the pain comes back. You can do this, but scars still there. She's 20 years old and still having surgeries. You sit there and all I want to do is make her life easier.*

Alyssa has, and will continue to protect and provide for her sister; whether it means not playing a sport in childhood because it pained her to watch her sister on the sidelines, to fist fights during their school aged years combating childhood cruelty, to holding down multiple jobs—also recognized as a coping mechanism to keep her mind distracted—ensuring bills stay current after one of Tiffany's countless surgeries. All things she is certain her sister would also do for her. What does ease her guilt though is feeling that "*[she] would be robbing Tiffany of a blessing if [she] were to trade places with her.*" She explains,

Tiffany being burned gave her the burn community. She's happy the way she is. She wouldn't have the self-confidence, she wouldn't know the people she knows, and who knows, I may have handled it differently. But Tiffany, she wouldn't be as strong as she is, she wouldn't be the person who she is, her smile wouldn't shine as bright as it does, and I would take that away from her if I were to trade places.

Although the burn community was a place of healing for Tiffany, Alyssa continued to wrestle with her emotions. A couple years following Tiffany's injury, she began attending a burn camp that was recommended by her surgeon. Alyssa asked her mom what she should do in her sister's absence, to which her mom replied, *"Go be a kid."* This was a statement that "*had no meaning to [her],*" adding, "*That was taken from me. I had to grow up really quick.*" She felt lost and alone. Alyssa had friends in childhood, "*but [her] friends didn't want to come near Tiffany, so [she] dropped [her] friends.*" Alyssa saw the excitement on her sister's face about attending camp that initial summer and knew she had to let her go; yet, she and her brother questioned what they would do in her absence, confessing "*All we [knew was] taking care of Tiffany.*"

Alyssa wanted to tell Tiffany how she hated burn camp and questioned her desire to return each year. She explains, "*Tiffany shifted into another community, but it left me kind of on an island, because I'm like, 'I'm the sister, what am I supposed to do? I've been through it all too, I've seen it all.'*" Alyssa confesses that when they dropped Tiffany off at camp one year, the twins were 7 or 8 years, she told one of the volunteers at the camp, "*I wish I was burned so I could come.*" Adding insult to injury, she reports Tiffany's friends and other volunteers told her they wished she could stay, to which she challenged, "*Why can't I? My house burned down too. I've lost just as much. Only thing, I got out.*" Moreover, not only did Tiffany have fun at camp,

she made friends—people she could connect and talk to—leaving Alyssa to think, "*Who am I supposed to talk to? Who understands my situation?*"

About a decade later when Alyssa was 17 years old—a year before she "aged out" of the program, a point she is still a little disgruntled about—the organization that hosted the burn camp Tiffany attended established a weekend program that included siblings. Alyssa went and recognizes she got a lot out of the program. Specifically, she recalls a peer support group facilitated by professionals where she shared thoughts and feelings, she "*didn't even know I was holding in, that I was angry about.*" Alyssa also realized some of her strategies for responding to the public about her sister may not have been the most productive. For example,

> *School was very hard. Someone said anything offensive towards Tiffany's burns, I was*
>
> *that kid that swung. Of course, my parents always taught me, never throw the first punch,*
>
> *but I felt their words were the first punch. Got in trouble a lot, stayed in trouble.*

After the peer group she professes her attitude changed and she learned, "*[E]ducate before you ever start swinging…They don't understand. They don't have the understanding you do. They don't know what you've been through to see them like that.*"

Alyssa also recognized her experience was valued by other uninjured siblings looking for support. She granted them permission to hurt and share their feelings—something she "*robbed*" herself of, sensing a void of individuals in her life that could provide her that type of support. One of her highlights during the weekend came immediately after the peer group, when an uninjured sibling approached her and declared, "*This is what I've been waiting for…is someone just to tell me that it's okay…I don't have anybody to talk to about this. We don't have other burned kids around.*" Neither had Alyssa, recounting how it was her first time meeting other uninjured siblings—outside her brother Tyler—who shared her similar experience; yet, her sister

attended a program for 14 years where "*[s]he's finding understanding and I'm back on my island.*" So after almost 17 years of holding things inside, she summed up her experience that weekend, especially the peer support group as, "*[I]t was just awesome. It was a weight that I didn't even know I carried.*"

There was a natural wax and wane in relationships over the years, yet overall the family remains steadfast to date. Alyssa explains,

> *We're closer more with our mom than we are dad, but you know how girls grow up to be their mom's best friend. My brother's really close with my dad. We're just a really knit, close family. I do believe it's because of the burn…[and] the house fire.*

One of the fondest memories with her sister is from a time when they were around 13 years old. While Alyssa changed one of Tiffany's bandages, she looked at Alyssa and said, "*Thank you.*" Alyssa questioned why, thinking it was for the dressing change—a task she had done often over the years. Tiffany replied, "*For loving me even though I put you through all of this.*" Alyssa grasped her gratitude was for far more than that bandage change, it was a lifetime of thank yous for enduring all she had.

Alyssa accepts Tiffany was closest to her parents during the hospitalization; however, once she returned home and began healing, she details,

> *[We] got really close. The closer we got, the more we kind of drifted from our family. We stayed in our own little bubble. Of course, [Tiffany] was still close with my parents because she had to rely on them the most, but later on down the road we realized what can and can't happen and it just made us, we're just a really close family.*

This sense of community stretches into the extended family and is further demonstrated by the eight people residing under the family roof for various reasons (e.g. caregiving for their

grandfather after their grandmother passed away, helping another relative going through a divorce).

Similar to relationships, family communication has ebbed and flowed as well. When asked about conversations regarding what transpired when she was 3 years old Alyssa replies,

My mom we can talk more about injuries. My dad, we don't talk about it. My dad's still very sensitive to it. My dad's this big ole burly manly man. So, watching him cry, it sucks, so we don't talk about it. That's the only thing that we've ever seen that would make him cry. I get it, he saved her. He's the one who had to run into hell to get her. My mom, she was a caretaker afterwards. We'll talk more about burns and everything… It used to be really strong when we were younger, talk about the safety and how things work and what really happened, but now it's like, 17 years later, we're moving on the 'moving on' stage.

In terms of conversations about feelings or emotions Alyssa notes, "*It's almost non-existent.*" When she was younger Alyssa remembers her mom telling her, "*Alyssa, we haven't forgot about you. You're still our kid…I still love you,*" with sporadic "*fun days*" where she got out of school early; however, "*[I]t'd kind of be left at that, we'd go back to our normal routine of taking care of Tiffany and that was kind of it. We don't really talk about it.*" When she returned from the weekend sibling program, she recalls a conversation with her brother that was 14 years in the making. It also compelled her to consider he had his own experience after the incident; hence, now instead of Alyssa Island—population one—her island underwent a census boom, with occupants that included her brother and the uninjured siblings she met during the program.

When Alyssa asked Tyler how he felt about what happened to Tiffany he replied, "*My little sister was hurt. I couldn't protect her. Of course, I hurt all the time. I was your big brother, but I didn't cause that, so it sucked. I didn't know how to fix it either.*" She encouraged him to see

her as a person he could talk with and he replied, "*Why? It happened…At least we didn't get burned.*" There it was again. She reminded him that was what they were told growing up, adding "*We may not have got burned, but we got burned.*" Although hearing, "*Hey, at least you weren't burned,*" from her parents and other relatives triggered an exile to her emotional island where she subsequently shut down—regardless of how benevolent it was meant—she is not upset with her parents understanding they tried "*to be sentimental to it and everything, but [they were] watching their own kid hurting.*"

Alyssa's conversations with her sister over the years were dialed into emotions, but more so Tiffany's. Alyssa feared her sister's depression and the guilt she expressed about what she put the family through, and reminded Tiffany, "*You made this life, this awesome life that we have, this person that we have become, you did that.*" Yet, despite the closeness, Alyssa articulates several times when discussing their relationship that she still tempers her own emotions from Tiffany in an attempt to protect to her. She acknowledges,

> *I've had plenty of opportunities to share with Tiffany, but I chose not to bring it up…Because I feel like it would hurt her all over again. I would bring it all back up, stuff that we moved on from or say we moved on from or just bottled up. I would open that bottle…but I'd rather cause me more damage than cause all of us more damage.*

She adds,

> *We all pick our people we like to open up to and it's—I would like to say Tiffany's my person I would open up to, but she's not. She's the person I take care of. It's hard to switch roles because I want to see—I've always been seen as the strong person to her. I feel like if I open up to her, I'm not that person anymore.*

Alyssa reports that instead of having one person to confide in she has multiple people, detailing, "*[T]hat way I can't have it like I do with Tiffany. If I need to switch roles with them, I don't want that to hold me back… It's really hard to rely on just one person.*"

Alyssa articulates a very distinct role within the context of her relationship with Tiffany, "*I'm a protector. I'm her person. I'm the one she always calls.*" At times she admits the responsibility feels heavy,

> *During surgeries it becomes a lot. Trying to move on with my life and build my own life and also trying to keep up that old life that I have with Tiffany, not old life, but part of my life, they do tend to outweigh each other at times, but I always make them work.*

When forced to consider the option of taking a direction in life that would benefit herself or Tiffany, Alyssa remains resolute, though not without some internal conflict,

> *It's something I kick myself for and I kick myself for kicking myself. I always chose Tiffany and I know if I'd made that other decision my life would be so much easier. I know it would put me where I wanted to be, but I'd be hurting Tiffany doing it. I'd be leaving her behind, I'd be veering away from her, so I chose her. Then, I'd kick myself because I chose her, then I'd kick myself because I doubted it. She's always been my number one.*

Alyssa's 10-year-old self-aspired to be the first woman firefighter in her local community, declaring she was "*going to save that kid. That kid that reminds me of my sister, I'm going to save them. I'm going to give them a better chance and I'm going to get to them before the fire does.*" Although not currently in the fire service, Alyssa was active in a fire service explorer program with her sister for a number of years. Fire Explorer programs provide youth (ages may vary by department) with an interest in the fire service an opportunity to learn what it

takes to be a professional firefighter and train—mentally and physically—under the supervision of other skilled professionals (Exploring, 2019). Instead she now works as a 911 dispatch officer, while still considering other public service careers.

Alyssa asserts she does not "*take in the negative anymore,*" and beams with pride when she brags on her sister Tiffany and how she shares her story at churches, civic groups, fire departments, or other public opportunities. Often Alyssa is the one setting up the speaking engagements. When asked if they ever shared their story together from multiple perspectives she denies adding, "*I never talk in front of people. It's not a fear or anything, it's just Tiffany had a better message than I did, so I let her speak it.*" Although she may not take to the stage, she candidly shared what she wished other people understood about burn injuries,

> *[T]he one thing people just need to know is the whole family goes through it…Everything becomes about [the injured individual], so does your life. So when people try to get past them and into your life, that's where you come out of your comfort zone because—and that's one thing that I struggle with—people try to get to know me and I end up talking about Tiffany, talking about everything else. I don't know how to let them get to know me because Tiffany's story became my story.*

Alyssa often found comfort in things being about Tiffany, acknowledging she got "*to hide behind her story so people didn't ask how I was and what I thought about it;*" yet, she also struggled to disentangle her own story, concluding,

> *I think my story is beginning. I have a past, but I based it around Tiffany. Instead of trying to find my story, I'm rewriting… My ground zero is now. Build off of who I already am and re-sculpt to be better. I figured might as well stop wasting time trying to fix everything in the past, what I've already done, and kind of better the future for myself.*

Artifact. Alyssa was not able to physically produce the artifact she wanted to represent her relationship with her sister Tiffany; however, she verbally described the item,

> It's a picture. Me and Tiffany were probably about four or five in it and we're out in the yard. Tiffany's just learning how to walk and I'm the one that's guiding her, then we both just look at the camera and smile as we're walking." She asserts, "*It just kind of describes exactly how we are today… Me and Tiffany are very close…Tiffany's the one person that I would do anything for.*

In her depiction of the image, she specified she was helping Tiffany, perceiving it as a literal example of their entire relationship. She explains,

> [W]e complement each other well. I'm the one that helps her and she's the one that needs help, but Tiffany gave me that purpose as a sibling. She gave me the purpose to be helping and it just shows how our relationship just worked. Tiffany needed help, I was there. Tiffany gave me a purpose to be there. I know being young you're not thinking about it like that, but when you look back, it's exactly how it's supposed to be. Without that picture, without that situation, we wouldn't be who we're supposed to be.

Amber

It was about 7:30 a.m. on a warm, sunny morning at the end of March—the day after her dad's birthday—and everyone in the house was asleep. The five siblings were dispersed between three rooms—the middle brother had his own room; the two youngest brothers shared a room; and the two girls, the first and second oldest, shared a room. The younger brothers liked to take turns sleeping in their sisters' room, so it was common for one of the girls to go sleep in their room and vice versa. This particular night, Amber and Cody, 13 and 5 years old respectively,

were sleeping in Amber's room—her on the bottom bunk and Cody on the top. Their dad was downstairs asleep on the couch. Amber describes,

> *I smelled smoke and then I just ran and I just, all I remember is screaming that [I] smelled smoke, fire, then run [sic] out of the house. Then my dad was trying to get us all out of the house and thought we were all out, but he knew Cody was still there…I just remember the smell at that point… just screaming and yelling from everybody trying to get out.*

Amber recalls her and three of her siblings in their pajamas "*just ran out of the house and then just stood outside on the street, that's pretty much what we did. There was no action plan or nothing, we just ran.*" Her dad ran across the street to solicit the help of his best friend. Knowing Cody was still inside he "*climbed up over the stairs, tried to go in the house, but the stairs had— the fire was coming down over him and flaming balls coming down.*" He then engaged the help of his best friend. Amber details how they placed a ladder on the exterior of the home—his friend holding the base steady—and her dad "*went up the two story, pulled Cody out and then all I remember was his skin hanging off him.*" Amber chronicles her most memorable moment and the shock she felt when she saw her brother,

> *[He was] laying on the ground with pretty much bones popping out and skin hanging off. I knew he wasn't going to be the same. That was hard. Yeah, seeing him on the—and everything just scorched off, that was rough…You could see his bone and you could see everything. His ears were burnt off, his nose, yeah, you couldn't even, you wouldn't even—it looked like someone that was [sic] just came from the dead pretty much. Yeah, it was bad.*

The well-intended comments that followed suggesting her brother would be okay were far from helpful. Amber thought, "*I'd seen him out of the fire and what he looked like. I wish people didn't have to continuously say that because they didn't physically see what he looked like out of the fire.*"

Amber's sister flagged down their neighbor, who was also a nurse, on her way to work and she called for an ambulance. Amber vaguely remembers firefighters arriving after the ambulance, because she and her other siblings were sent down the street to their maternal grandmother's house. Both Amber's dad and her brother were rushed to the closest burn center because the local hospital was not equipped to deal with their injuries. During his son's rescue Amber's dad sustained burns to 35% of his body—primarily on his forehead, arms and hands—and spent approximately two months in the hospital. Cody sustained third degree burns to 85% of his entire body and endured a six-month hospitalization.

The first or second day of Cody's acute hospitalization there was grave concern over the possible amputation of his leg, and he was transferred to another burn center—over 1500 miles away. The new facility was not only far away from his home, it was in the bordering country requiring lengthy travel by car and further complicated by the need for multiple ferries. Amber's paternal aunt, Sue, stayed with Cody at the new hospital until their dad was discharged and able to get to his son. Amber was close to her Aunt Sue disclosing, "*[S]he was pretty much my mom because my parents, they—my mom walked out on me when I was 10. Yeah, we were raised by my dad.*"

While her dad and brother were hospitalized, Amber and the rest of her siblings were cared for by other family members on their dad's side, including additional aunts and their grandmother. She states, "*They all took turns helping and watching us while they were in the*

hospital, so we could somewhat continue our normal life after what happened." Amber recounts seeing her family home, which her great-great-grandmother had given to her dad, for the first time,

> *[T]he house it was half falling down, there was some siding left, all smoky, you can tell it*
>
> *was pretty much totaled, that it was bulldozed down. There was no saving it…. It was*
>
> *hard. Well, I was young, so it's—now that I'm older, it was difficult, but I lost everything*
>
> *after, so not having no [sic] memories, no [sic] pictures…stuff like that, was hard.*

The first few days after the house fire—later determined caused by electrical issues—Amber was struck by the community's response. She was humbled by her local area's generosity, which she says is very common during times of crisis or for smaller needs, and adds the benevolence came from all over, especially after news broadcasts. She chronicles how people came out in droves "*trying to help, giving [to] us, donating, trying to find us a house, making sure that we were busy all the time so we weren't thinking about it, trying to get us back into our normal routine.*"

Initially, they stayed in a home provided by their local social service agency; however, the community raised money and Amber reports they "*actually bought us a house*" that included all the furnishings, which helped take some of the stress off their father. She and her siblings stayed out of school the first few days, but it was not long before they returned to school and sports in what she perceived as attempts to refocus them on "*the positive that was going before than [sic] the negative… to make sure homework was getting done, we were socializing with our friends, stuff like that.*" When she did go back to school Amber describes,

> *It was [a] shock because everyone asked questions and I didn't know what to say, so I*
>
> *would always avoid it, so I didn't have to deal with it because I didn't want to. But a lot of*

questions and ask [sic] why did it happen, how did it happen, stuff like that. It was hard

for a bit.

Amber reveals it was difficult, stating, "*I was still blaming myself. I think I didn't want to face that at the time for my own sake because I was blaming myself, but people were telling me that it wasn't my fault and stuff like that.*" She knows these questions from peers were challenging because they were the same ones she had been asking herself over and over; so, she would change the subject and discuss sports, inquiring about practices and tournaments.

While her dad and brother were hospitalized Amber relates thinking, "*I was going to lose my brother and that my dad was pretty much going to be disabled.*" She felt confused by the mixed messages about her brother's prognosis adding,

> *[S]ome people were saying he was going to make it, some people were saying he's going to die, but, so it was a mixture of both that he was going to make it, going to die. At that age, I didn't know what to expect.*

Amber concedes she continues to grapple with feelings of blame and responsibility for Cody's injuries. She admits replaying the events of that night many times, wishing "*[I] just grabbed him with me so that wouldn't have happened if I was thinking better, but it's the same over and over, 'Why, why, why?' Pretty much. I still haven't gotten that answer.*" She recalls a priest at her grandmother's house telling her not to blame herself; but the ambivalent messages persisted and "*by hearing everybody else, it was a mixture of everything, so I kept blaming myself, still to this day.*" Amber defends her sustained responsibility for Cody by her position as the eldest sibling, especially after their mom left. She declares she took on the role of her siblings' mom at the young age of 10 and acknowledges it was a heavy burden, adding, "*I had a one and two-year-old to look after.*"

Amber and her siblings did not see Cody the entire six months he was hospitalized. Instead, she says,

> *[We saw] pictures that my aunt sent us from [the hospital] or what we heard on the news or talked to him on the phone; but we did not see him for the time he was away and getting fixed.*

Amber longed to see her brother explaining,

> *[E]very time we talked to him it was hard because he couldn't really hear us because he was in ICU so he had a bubble over him, plastic, so he couldn't really have too many people. He couldn't even hear the phones because of the plastic. It was hard.*

When Cody was finally discharged from the hospital, he was welcomed home by a parade. They were still in the temporary housing provided by social services and Amber remembers how Cody laid on his bed and "*sprawled out with his arms open. He just said, 'Thank God I'm home.'*" It was an emotional moment for Amber as well, recounting how for months it was uncertain whether he would live or die. Although her brother was home and they were all finally reunited she details,

> *[W]e also had to deal with the changes that we had to go [through] with seeing Cody's bandages changed every day, going to therapy with him…making sure he's walking, keeping him active so he didn't seize up and stuff. It was good that we were in a family, but we had to go and adapt to changes that he had to do and what he had to do to come to recover and having to come and go. He could be home for a few months, go again for another month or so, a week, come back again. That was adjustment that we, as siblings, had to get through.*

They had access to physical/occupational therapists, though it was a boat ride away, which made for a full 6-hour day, roundtrip, several times a week. Amber reports she went to most of Cody's appointments when she could, especially if it was during summer and she did not have school. Additionally, due to his healing injuries they had to be more careful now with how they touched and played with him; yet, Amber admits, "*I didn't care, I always treated him like my other brothers, even when he was burned. I threw him around. I played with him. I fought with him. I didn't see any different.*"

Before the house fire, Amber characterizes the family relationship as "*okay*," but adds, "*I felt like I was pretty much the one to the side, just due to all the responsibilities and everything.*" She admits, "*School got neglected on my end a little bit…but I just kept it going.*" The family spent time together at all the holidays and she recollects playing outside, sliding and skating with her siblings, and lightheartedly includes "*fighting, of course.*" A highlight before her brother's injury, was when Amber received a gold medal in competitive figure skating at 8 years old, stating she contended against girls 10 years her senior. Though she had been involved in figure skating, volleyball, hockey and wrestling, the only sport she maintained was volleyball, noting that things had gotten too expensive for her dad—stressing it did not have anything to do with Cody's injury. She found comfort in the words of encouragement from her volleyball coach— geared at sports, but also with a fine-tuned awareness of her family's situation.

In the months and years after the house fire and injury, Amber confides the biggest change to their family was Cody's absence. Additionally,

> [His] *flying back and forth, being in the hospital for surgeries, not knowing… [who] we're going to have to stay with and stuff like that. It was always on a roller coaster up and down what was going to happen. It was never a solid family, there's always*

something going. You never know [if] your brother had to go or how long he was going

for...especially where he had so many surgeries growing up. I don't even know how many

he's had now, to be honest. It's been a lot.

This sense of instability endured until they were given their new home; yet, they were still being shuffled back and forth between family members since caring for four kids was a lot to manage and Cody remained intermittently hospitalized, or, in need of ongoing medical treatment. Amber recalls the sense of confusion about how to behave, "*It was always a guessing game and us trying to figure out if we should be good, be bad, just trying to be kids and teenagers growing up.*"

Their mom did make an attempt to see Cody when he was injured, flying down to see him; however, the family "*rejected her to see [sic] him. After that, she pretty much stayed out of the picture just because of the family and what they did.*" Years later, when she was 18, Amber reached out to her mom and invited her to her graduation, which she did attend. After that they lost touch until she was 23 years old and Amber remarks, "*Till this day now, we're pretty, she's my mom, but we're more friends…not mother, daughter.*" Cody made contact with her just a few years ago, but Amber reports their exchange was strained concluding, "*[S]he wouldn't give him the answers he wanted, so he doesn't really care. He more or less thinks [of] me of [sic] a mom than her.*" Her other siblings shared Cody's sentiments in childhood insisting, "*She's not my mom. You're my mom.*"

In terms of the sibling relationships, Amber discloses,

I felt like it separated the siblings a bit. Some of them got jealous because Cody was

getting a lot of attention. I know it brought me and Cody probably the closest together

since all that happened. There was a little bit of jealousy, fighting more a little bit, just

because he was getting all the attention, nobody else was getting the attention, especially my middle brother…We all took it out on each other instead of helping each other out.

Amber admits her brothers were not the only ones with ambivalent feelings, explaining,

There's times I still feel that way, yes. Not going to lie. It is what it is. I just wish I had the help he had to do what he was doing right now…Because I was such a young person, I left my help, parents, when I was 18 so no one was ever there for me. He was lucky to have people there helping him out for school, for everything. So, he was lucky to have the life he has right now.

Nonetheless, she reiterates, "*We're still close so that's all that matters to me.*"

The conversations with Cody now about his injury are minimal,

We don't even see that now anymore. It's just a normal conversation now…We talk that he needs to get his surgery done on his skin because his stomach is tightened…Other than that, it's normal conversations. It's no talk of him being burned unless he's going doing something supportive, like the group meetings that I'm going to be attending with him and stuff like that.

Yet, confiding in him the guilt she carries is mostly off topic. She advises Cody does know some sharing,

[T]here was one time we talked about it, but I cut it off. I just told him a little bit and then he knows a general little bit of how I feel because I talked to him once but didn't go through with the whole details because I got too worked up.

She further elucidates,

I don't want to beat him down or anything and if I have [the conversation], I just would probably have it with somebody else just to get it off my chest because he's doing so good, but I don't want to see him feel bad for me.

Amber refutes it feels like an obvious issue going unaddressed, suggesting because they have a strong relationship "*everything else overpowers that feeling so I don't really think that way.*"

As for the family's current status, Amber says she primarily keeps in touch with Cody, continuing, "*I talk to [the rest of the family] when I need to, but that's pretty much it.*" She and her brother both moved from their home town to roughly the opposite side of the country, about 2,300 miles away, although for different reasons. They keep in touch with their other siblings as best they are able to around work schedules. She states they both talk to their dad, "*[W]hen we can. Pretty much, that's it;*" though, since their other siblings remain geographically closer to him, she assumes they stay in closer contact. She further reveals, "*As I got older, stuff happened, so my relationship is not very good with [my dad] due to stuff that happened in the past.*"

Outside the tangible items provided from the community, Amber does not remember specific resources offered to her following the house fire. Her brother attended burn camp and other holiday events following his burn injury. Her dad got involved with the Shriners and the Masons. Alternatively, she narrates, "*I just dealt with it by myself. Never had nobody [sic] there. It was just dealing with it on my own all the time, kept it inside.*" Even now, Amber acknowledges she is still keeping things from her family. Nightmares and hypervigilance followed for years. She describes,

I've woken up with the smell of smoke in my nose a lot. It was always I have that smell in my nose sometimes. Until I was about 17, so for four years I would wake up with that. After that, I always made sure Cody was always by me, so I knew if anything happened, I

made sure he was there with me so I could take him right away… There was one time I did have a nightmare, I think I was 23 at the time, and I heard fire trucks and it woke me up and I thought I was stuck in a fire burning. Every now and then, but I haven't had anything recently. Once in a while triggers, especially if I like see fire or hear the sirens or even see it on TV…sometimes that might trigger.

Amber perceives her life as one filled with struggle, often feeling alone, and pushed to the side, remarking, "*[T]he outcast—doing everything on my own…except my aunt who was there who passed away, but other than that, it was me just trying to get by in my life.*" She grieved her teenage years spent raising siblings and moved out when she was 18 years old and established "*some bad habits.*" She discloses a period of time after being on her own where she engaged in drug and alcohol use; nonetheless, she championed her recovery, humblebragging,

[I] cleaned myself up, went to school, graduated school, went to nursing, [and] got my healthcare aid. When people said I wasn't going to graduate, going to have kids when I was young, so I proved all that wrong. Pretty much fought for everything I have right now.

Her family was unaware of the severity of her substance use, but she credits Cody as her source for ongoing support who continues to check in on her.

Amber is back in school and has a fiancé and a 3-year-old son. She stays busy working multiple jobs, which she also did when she was pregnant, and rationalizes as why her son is so active all the time. She is a proud sister and distinguishes Cody as "*so strong to be able to fight*" and thrive. After almost 20 years, Amber acknowledges this the first time she has told her story and admits, "*[I]t's hard for me to talk about it.*" Her hope is for people to understand the impact of the burn injury on the family, suggesting,

Just try to talk to the family, siblings. Right off the hop, don't just push them to the side because in the long run, that'll affect them in the long run. Try to be there for them during, just as much as you are for the burn victim, because it will affect them longer down the road, what they are holding back, instead of letting them talk right away.

She aspires for people to be honest and supportive, continuing, "*I know my family got separated because of everything. We fell apart more than getting closer, but that should be the time they should be there for each other more no matter if someone is getting more attention.*" When asked to reflect back on her experience she remarks,

It made me a better person. More willing to help people who's [sic] in need because I needed help. When I hear stuff on the news, especially when it comes to fires or burn victims, even hearing the fire truck and stuff like that, I'm always anxious to see what's going on because I don't want them to go through what I went through because I know what struggles was [sic] like… it can happen to anybody and you don't know if it's going to be you one day.

Artifact. Amber was unable to produce the actual item but evoked the artifact she wanted to illustrate her relationship with her brother. She verbalized it was a photo of her brother wearing a fire helmet standing up in a firetruck alongside another firefighter. The image was taken at the burn camp he attended as a child. Amber explained the relevance of the photo's symbolism observing, "*[H]ow strong Cody is because, fire, to me, can be strong sometimes…[H]e was so strong to be able to fight through everything that he's still standing till today.*" She also finds importance in the relationship between the truck's capacity for speed and Cody's ability to recovery quickly from his injuries. Interestingly, she chose an image that does not include her. When asked about it, she replied,

To be honest, I don't know, it was just that picture reminds me of how hard he fought to go through everything. Even if I wasn't there, he was still fighting. Yeah, I don't need to be there more or less because I know he's still going to fight no matter what.

Isaac

It was their grandmother's birthday—most likely October or somewhere near fall—and the entire side of his dad's family gathered together at a Chinese restaurant to celebrate. Since there were so many people in attendance the family had a private room. Isaac was 3 years old at the time and recalls,

I don't really remember a whole lot about the day, but I remember when it happened. I was just sitting at the table doing my 3-year-old thing, just I guess aggravating my grandma, and we heard a really loud scream.

The scream was Noah, Isaac's 6-year-old brother, and he immediately felt confused by the ensuing chaos of the adults "*just up and running. It was a full-on sprint…They had to go find the scream.*"

Isaac remained with his grandmother and she offered words of comfort. Noah and his Dad had gone to the restroom, which was stationed directly across from the kitchen door. Just before the scream Isaac recounts, "*I heard the pan hit the ground…I guess it was carpet. I just remember hearing a, 'Bong,' and it was boiling soup. It was really, really hot, I'm assuming.*" Isaac reasons that the server and his brother came out of the kitchen and bathroom, respectively, at the same time. The server had a pot and, unable to see Noah because he was so short, he conceives they collided into each other, resulting in the contents of the pot spilling onto him.

Isaac states no one ever told him what happened, but recollects, "*[A]n ambulance crew coming in and they wouldn't let me go see him when it happened. I had to sit there and then*

watch them take him out." His mother rode in the ambulance with his brother, which he thinks the restaurant staff called, and his dad retrieved him from the private dining room, and they drove to the hospital. Isaac denies the moment evoking any particular feelings about what happened. Although he reiterates not remembering all the specifics from the day, he details with certainty how scary it was seeing Noah for the first time once they arrived at the hospital,

> *I do remember going in and seeing him laying on a bed and he was completely out of it. I think they had him on some type of drug or something. He had his eyes open, was completely unresponsive, [and] wouldn't say a word. He had a bunch of gauze and a lot of other stuff placed on his neck…Those doctors really sent my brother home that day saying, "Oh, it's just a burn. Put a [sic] ice pack on it." As a kid, I didn't really know what that was, but my brother was crying in pain when they sent him home. He was freaking out. His neck melted, basically.*

Isaac's parents took him to see another doctor he believes the next day—although admittedly the timeline is a little unclear to him—and they suggested his parents immediately take Noah to the local burn center for treatment.

When Noah relocated to the burn center Isaac stayed with his aunt for a few days while his parents remained at the hospital. After a few days his dad came to his aunt's house and took Isaac to see his brother. Isaac narrates,

> *That's when I kind of saw what had actually happened. It wasn't covered up and it was pretty gruesome. It completely maimed the side of his neck and he had a big spot on his back where it'd burned him. He was in a lively spirit for the most part. He handled it really well.*

Other than the memories of what he saw and having to leave the room often when the nurses came in to care for Noah, nothing else stands out from that visit at the burn center. Yet he concedes,

> *I think that was the first time in my memories where Noah was considered my brother…because I didn't really acknowledge his existence until I was probably about that age. I knew he was just a kid that was around me when I was a baby, but I think….that's really the point that made me remember that he is my brother. That's where it went from there.*

After the initial hospitalization, Isaac reports "*it just kind of went to a blur*" and the family began a series of trips for ongoing medical treatment at a specialty hospital. He adds, "*I don't even know how often, but it was a lot. We went up there a lot.*" He says "*we*" because early on, when Isaac was younger, he traveled with his family adding,

> *Usually for the really big surgeries and stuff, I'd be up there, but if it was later on in life when he was just doing the laser surgeries, getting the hair removed out of the skin graft, I wouldn't really go up there.*

If his brother needed to go to the specialty hospital once Isaac was school age, he assumes he most likely stayed with his aunt, though he admits, "*I'm guessing. I can't really remember that well.*" However, he furthers, "*I know for the most part, one of them usually tried to stay home, if I had to stay home.*" His mother did not work until Isaac was around 10 years old, so if she went with Noah he would stay home with his dad or vice versa. If he did go with his parents, they would sometimes stay at the hospital or with his parents' friends who lived nearby; however, he reports they tried to schedule surgeries during winter and summer breaks to avoid extended absences from school. Those trips often turned into quasi-vacations for the family, since they

would visit with their friends and do things in the area, as well as make stops to and from the hospital to sight see. Aside from those trips, the family also vacationed some at the beach. Isaac recalls, "*I do have really good memories of my parents going on vacation and stuff.*"

Due to Noah's limited physical activity after he was injured, video games became a huge part of the brothers' lives. Isaac reports,

> *After he had gotten burned, for probably the first couple of years, he couldn't do*
> *baseball, he couldn't do all that stuff and he was at the age of six, so that was right*
> *around the time the little leagues and all that stuff started to come into play.*

Therefore, the boys would remain inside and play video games or watch Saturday morning cartoons. Isaac speculates had it not been for his brother's injury and his need to stay indoors he interest in gaming may not have been piqued. Isaac reports he establishes most all of his friendships online with gamers and thinks they share in common being introverted, which is something he perceives as "*kind of a bad thing.*" He clarifies it "*caused a lot of issues growing up,*" referencing struggles with depression over the years, which he kept from his family. He attributes his girlfriend as someone who has "*really helped [him] get out of his shell,*" by filling the void of a confident with whom he could share his thoughts and feelings.

The brothers were in the same school during their high school years, often missing each other by a year at other points in time. Fielding questions about what happened to his brother when they were younger was a frequent occurrence, particularly if they met a new group of kids in the neighborhood or church. He says he never gave much thought to how he felt about answering those questions, continuing, "*I knew why they weren't asking him, just because that was, I guess, it'd be kind of rude to ask about, 'What happened to you?'*" He explains,

[T]hey would ask me about it because they didn't want to ask him personally because something had happened to him. They knew I was his brother, so they'd ask me what happened because it was very, very visible when he was a child before he had all the skin graft surgeries. It was a big clump of scar tissue that was bright red. It popped out. Everybody saw it. That was the first thing they saw when they looked at him. I'd get questioned like "What happened?" but never anything on the malicious side. I never knew anybody to be mean about it.

Isaac reports, "*Even [Noah] says, growing up, he didn't have a lot of people make fun of him.*" Yet, he adds, "*He got called 'burn boy' a few times*," which he clarifies as, "*something kids do. They identify the most identifiable characteristic of a person.*" Isaac recognizes how that could have been upsetting to his brother, disclosing his own experience in childhood, "*I was bullied a little bit when I was growing up in school, but that was mostly because of my weight, one, and the other one would just be my introvertedness, not really talking to people.*"

When considering what it was like to grow up with his brother who sustained a burn injury in childhood, Isaac describes,

The big thing is just, I guess it was I felt like he got more attention than I did from my parents. Mostly by physical possessions and stuff that he would be given….It was just, I saw them show a lot of attention to him. We [also] couldn't really go do a lot of stuff.

However, he acknowledges, "*Yeah, they'd show him a lot more attention because he needed it. He was going through a lot of stuff.*" Specifically, he recalls the neck brace after surgeries, as well as,

[T]his little shirt [pressure garment] that was really, really tight…he hated those, and I

remember that was something that was a big deal with him. He would be crying because

he had to wear it and it was so tight on him.

Aside from the jealousy he felt about the attention his brother received from his parents, he also felt envious of his brother getting to attend burn camp every summer. The first summer he denies thinking too much about it; however, when Noah returned home excitedly sharing all the things he did at camp, such as super soaker water fights and swimming in a pool, Isaac altered his position. He was glad his brother was able to go, but admits, "*I was a little jealous of him going to camp because I was like, 'I want to go do stuff like that.'*" Not to mention Isaac said he typically spent his week at home playing video games after dropping his brother off at camp and witnessing first hand all the fun he would have. He adds, "*I kind of did feel like I wanted to be a part of all of that, but I wasn't the one that was burned so it was for my brother.*" The camp program his brother attended began to include siblings several years after he and his brother both aged out of camp. Reflecting back on his missed chance, he concludes, "*I think it's probably a good thing [to include uninjured siblings],*" especially since he denies any specific support for him in childhood and admits he would have liked to attend had he been afforded the opportunity.

Following the incident at the restaurant Noah's parents filed a lawsuit. The restaurant took responsibility and after almost 10 years the situation was resolved in Noah's favor. Isaac attributes the delay in proceedings to his parents' first lawyer who failed to do anything with the case, which resulted in his parents seeking new counsel. Finally, when Noah was about 16 years old, he was awarded the settlement. Isaac shares,

[T]hat was a really big deal. He was able to get whatever he wanted. He bought himself

a car, he got literally just—when you give a 16-year-old money, they're going to—He did

really stupid things with his money and my parents, they got a little bit around that time, too.

He adds,

> *My parents were awarded a little bit for the troubles of having to go through all of that. They were given an amount and most of it was structured around my brother. My parents went through and they were able to allocate the funds…[and] how he would receive them like a structured settlement program and stuff like that.*

Based on the structure of the settlement, Noah will receive funds until he is 63 years old. Isaac believes initially it was structured to allow a certain amount of money until he turned 18 years old, followed by a set amount for college, then structured amounts every 6 months, and a lump sum to purchase a home. Isaac perceives,

> *He has always had a good bit of extra spending money. He was able to buy whatever the hell he wanted to buy. My parents knew that he had money, I knew he had money. If I wanted something, "Noah," but he wouldn't ever, he'd never break down and give me something.*

Instead, he received Noah's "*hand me downs.*" He offered the following as an example,

> *It was like, "Well, I got this Xbox 360, but I want this brand new one," so he'd buy the brand new one and he'd give me the old one but I still had to pay him for the old one, which I never paid him for. That was his idea, he wouldn't let me have anything for free, which is the way life is. Nothing's free in life.*

He also recognizes, that it "*got really tedious [for Noah] because everybody knew that he had a pretty penny of money.*"

However, Isaac discloses, "*At the time, it was very 'this is unfair.' I'll be honest, there was [sic] times where I kind of wished I'd gotten burned so I could have all of that.*" The feelings of frustration and envy began early after Noah was injured and the settlement just incited the existing dynamic. Isaac explains,

> *[H]e was always the first person to get anything because, one, he was the oldest, and two, he needed something to occupy his time because he didn't have the opportunity to go out and do a lot of other things that were outside, particularly. They really got everything for him first. I remember when he got the Game Boy, I was really upset about that as a kid because my grandma bought it for him because he had to do all these long drives up to [specialty hospital] ...He had to have something to occupy his time. My grandma bought him a Game Boy and from there, it just, I know the jealousy kind of grew into that because he got that, he got the Nintendo 64, and throughout my entire life, I would never actually get any of the stuff. I had to wait probably, I'd say, about a year or two after he'd gotten his first Game Boy for the Game Boy Colors to come out.*

The Christmas he and his brother got matching Game Boy Colors was memorable for him, *"[T]hat was one of the first things that, as far as a [sic] electronic device, my parents bought me. That was the first one that kind of touched home.*" However strong his feelings were at the time, Isaac comments, "*[H]e was always the first one to get anything like that because he was obviously, he needed it more. Looking back at it, he needed it more than I did at the time,*" but adds, "*As a kid, you're still kind of like, 'That's not fair.'*" So, when Noah received the settlement, Isaac saw it as part of *"[T]he cycle of him getting stuff [that] has continued still to this day.*" Yet he also asserts,

I see what it's done to him and I see where he's fallen short in life because when you, I guess when you receive that kind of money at a [sic] early age and you don't really know what to do with it.

As a result of the settlement, Isaac feels it set his brother up for a certain standard of living he may not always be able to maintain, commenting,

He over spends a lot of times on things. To see him throw away some of the things that he's been offered, such as college, he had full ride, everything he needed….and he did attend college, but he didn't care because he knew he was getting X amount of money till he was 63.

Apart from the actual settlement funds, Isaac feels his brother had other opportunities to access resources for school (e.g. scholarships) that he failed to utilize, whereas he perceived his options to finance college were far more limited. He notes,

I knew if I was going to college it was going to be something lower like a tech school or something. I completely gave up on university. I was like, "That's definitely not going to happen. I can't afford that." I didn't want to go into debt like I've seen.

Moreover, he admits, "*I never really thought about my future until a year after I got out of high school.*" At that time, he was working three jobs and thought to himself, "*This really sucks. I don't want to do this.*" He then considered college, but reports he was unable to secure financial aid due to family circumstances. Therefore, witnessing Noah's ability to finance school juxtaposed his appraised challenges to do so Isaac asserts, "*He threw it away. He went to school and played [video games].*" This resulted in Noah being placed on academic probation and subsequently withdrawing from school.

Though Isaac accepts envying Noah's resources, he also feels conflicted,

He's never really sought to do more with himself and I've just kind of seen him give up on a lot of things over the years, which is kind of tough for me because he's my brother. I don't think a kid at that age should have that kind of money to do what he wanted to do.

Isaac reports he tried talking to Noah about the situation with school, but states he is not very open to the discussion and once commented, "*College ain't for everybody.*" He agrees with his brother's sentiments, but reiterates, "*[I]t's just hard to see somebody given all that just throw it away into shoes and video games and whatever the hell he wanted to buy at the time.*"

Isaac and Noah have lived together their entire lives with the exception of the first year after Noah bought his home and needed to do some remodeling. Noah bought the house when he was 24 years old and Isaac admits that without his brother's settlement both of them would have most likely lived with their parents longer. He declares, "*I had to get out, which moving in with him, it was easy. He's my brother. I didn't have to worry about somebody stealing stuff from me if I moved into somebody else's house.*" Their plan to move in together was discussed in advance. He says,

> *Even with the payments that he's receiving, it's still not enough because he doesn't receive that much monthly, but it's like a paycheck for me. An extra paycheck, that'd be nice to have that…he'd be able to afford to live there, but he would not have anything. He'd be struggling to eat, so he needs roommates. He's not very good with his money…at all. He's probably the worst person I've ever seen with money. He does not know how to save it. He does not know how to manage it in the slightest, which I can't say I'm the best at it, but I'm still a little better.*

The brothers are both in committed relationships and Isaac realizes this may impact the timeline for how much longer they live together, which he admits would "*be kind of weird because I've been around him my entire life.*"

Within the context of the family Isaac notes,

[The burn injury] never really got brought up [in conversations] that much. Just, whenever it was getting time to go do something like [surgeries], it'd bring it up. Obviously, when Noah was wearing the shirts and the neck braces and stuff like that, he would often complain about it so that would bring it up. For the most part, I just kind of went on normal. It wasn't something that constantly was being presented in family life. We never really sat down and had discussions about it all the time. It was just more of, "Hey, it's something we gotta deal with and we deal with it."

However, in hindsight he suggests having someone to talk to would have been helpful, particularly,

[S]omebody that's not a part of the family. Somebody that you can sit down and actually probe for information. I don't think many children are going to willing fully [sic] say this kind of thing, so you'd have to be able to talk to them in a certain way to get out the information that you wanted from them to let them understand. Basically, you'd have to talk them into understanding their own feelings.

Having someone that is not part of the family is rationalized as a way to inoculate parents or others so that the kids can truly be honest about their feelings. Whereas, he describes,

My mother didn't handle things in a very sensible manner when I was a child. She would overcompensate for—if I told her [I felt we were treated unequal], it'd be, oh my gosh, she'd be overcompensating for it and be wanting to take me everywhere and do all this

stuff and I don't want her to do that because she feels like she's not doing it enough and it'd just be, I want my mother to be my mom. Pay me the equal amount of attention, which eventually, once things calmed down, I could see it really—it started to fade back to just normal, I guess, but for a long time there, I did have those feelings of just being "meh."

Generally speaking, Isaac affirms the brothers get along most of the time. He adds, "*[H]e's a jackass sometimes…[but] we've never had a bad relationship, I can say that. We've always been on good terms…We know what each other's weaknesses are and strengths and we just kind of go through life.*" The sense of inequity he felt in childhood has dissipated and is better understood to him as an adult. Furthermore, he denies its impact on him today. He continues,

> *We're mostly kind of seen as equals by our parents today. I think we probably were growing up, it's just at the time I didn't understand a lot of things, but I mean my parents, they love us both equally.*

Currently, he acknowledges friction in his relationship with his father related to his position as an atheist. They see each other daily at work and do interact; however, he notes, his dad distanced himself and things between the two of them are not the same. On the other hand, that did not impact his relationship with his mother, and he states that they, in fact, talk about it quite a bit. Isaac says Noah is similar to his father in terms of religion, so if anything creates a challenge in their relationship, it would be that; therefore, they avoid the topic, even though Isaac enjoys discussing politics and religion. He details,

> *The kind of relationship that we've always kind of established was just "be chill, don't really have any in depth conversations on a lot of things," we just kind of…were around*

each other…. Noah's also never been good with sharing how he feels at all. He doesn't

know how to come up with the words to express a way that he's feeling.

If Isaac has something important he needs to talk about he says he goes to others in his life, often

his gaming friends, who he feels are more inclined to provide honest feedback based on the

anonymity of the relationship.

In conclusion, Isaac recommends,

[P]eople probably should be more aware of their other child after something happens

that's traumatic to one of their children. He did get a lot of attention, a lot more attention,

and even [if] it wasn't positive attention—because it was always "I'm having to attend to

his needs"—but it was still attention. As a child, you seek attention in whatever form you

can get it. I started to act out as a kid a little bit…so I could get attention from my

parents. I don't want that to be something that goes unnoticed. I do think people do need

to acknowledge the fact that they do have another child that they also need to show

attention to during this time period this is happening. Remember that they do exist, which

I know is hard to do after something traumatic happens to one of your children.

About the time he started Pre-K, which was also just after his brother's burn injury, he recalled

feeling confused, adding, "*I didn't really know what was going on. I'd just get sent to school and*

that'd be that." He began acting out, commenting, "*I was that kid that, whenever they had*

naptime in Pre-K, I had to sleep right next to the teacher because I wasn't allowed to be

unsupervised." As he got older, he reports he began distancing himself from others and noticed

he was becoming more introverted, which he also speculates led to his experience with episodes

of bullying and depression.

Thinking through the chronology of his life and timeline of events he asserts,

[The burn injury] affected my life. Let's say if it never happened, I have no idea where the hell I'd be right now. What would I be doing? What kind of person would I be? Would I still be holding this [game console] in my hand right now? I don't know…it's so easy how life…just one thing in life can alter the entire course and, even if it didn't even directly happen to me, it set in motion a series of events that lead to me being where I am today.

Artifact. Isaac selected a Nintendo 64 controller as the artifact to represent his relationship with his brother (see Figure 2). Playing video games was something Isaac and Noah did often due to Noah's limited ability to participate in physical activities after sustaining his burn injury. Isaac notes, "*[F]or me to be able to still interact with my brother, we played video games.*" By the time his brother was physically able to participate in sports, Isaac admits, "*I wasn't a big fan of outdoor sports...[so] we didn't really have much in common growing up other than video games.*" Therefore, gaming remained the primary source of interaction for the brothers then, as well as today. Moreover, he proclaims the shared interest strengthened their relationship. This particular console was the first one he and his brother had, remarking, "*[O]ur parents bought it for him…still salty about that as a kid.*" Isaac being "*salty*" about the console speaks to his feelings around what he perceived as an inequity in treatment from his parents following his brother's injury, which as an adult today understands differently. He also believes the activity that started as a way to connect with his brother contributed to how he understands himself now, including identifying as more introverted, surmising, "*I think it really kind of jump started me as being a gamer because I am a huge gamer.*"

Oliver

Oliver, a few months shy of turning three, was at his grandparents' house and his 8-month-old brother Scott was at home with their parents. Scott had been sick, so Oliver assumes

he was staying with his grandparents to prevent him from getting sick also. Although he was young at the time, Oliver says he remembers when his brother was injured well. The house they grew up in had a wooden floor. He describes,

> *My parents were there with him and he was a very active baby and he scooted the crib across the floor, the crib had wheels on it, and he went over to the hot water vaporizer and he pulled the cord and pulled it down on top of himself.*

His dad subsequently filled a tub with ice and water and placed him in it before they took him to the hospital. Oliver acknowledges,

> *I wasn't actually there when it happened…but I remember him coming home from the hospital and they came to my grandparents' house to pick me up and he was covered in bandages everywhere and everything. My dad was holding him. I remember greeting them at the door and going, "Whoa, what is going on?" It looked pretty crazy.*

Scott's first hospitalization lasted several weeks, but Oliver was too young to visit; however, during his ongoing treatments and subsequent surgeries Oliver was older and could visit his brother, but proclaims, "*I did not like the hospital…I still don't like hospitals today.*" Once he was discharged home, Oliver details,

> *He was in and out, in and out constantly for skin releases and skin grafts and all that stuff and mostly I was at my grandparents' house, so when those things would happen, I was just there with them mostly. They lived close to us.*

Oliver denies Scott receiving any kind of specialized care at home following these succeeding treatments.

At 7 years old Oliver remembers watching television and seeing "*pictures of my brother, his skin grafts and his face and all that*" being flashed up on the screen because his doctor was

pioneering new ways of grafting skin. Although Oliver thought it "*was a trip*" to see his brother in the limelight, he felt a sense of relief about him being the focus. He clarified,

> *I never really wanted attention. I was better if they just left me alone. I was almost grateful that they were giving all the attention to my brother if that sounds weird or whatever, but it was like "Oh God, thanks. Just leave me be and give it to him.*

Yet his sister—born about three years after Scott—felt otherwise. While Oliver was thankful for being left alone, he reports his sister shared this opposite sentiment, "*Oh God, they're leaving me alone.*"

He speculates his mother "*really overcompensated*" with his brother after his injury. From a young age Oliver reports,

> *I felt like my parents weren't watching my brother and sister at all, so I felt like they were endangered many times. My mom would let my brother go walk along the edge of cliffs and go do things. My brother was a very adventurous child….Of course, I'd be freaking out all the time that something's going to happen to him…but that's just the kind of parents they are…There was always that thing of, "Oh God, I've got to protect these kids all the time"….I feel like my nature is to nurture anyway, so that's probably who I am no matter what.*

When he later asked his mom why she let Scott do the things Oliver felt were dangerous, she replied, "*I was building his confidence. I knew he was going to have a hard time.*" However, he believes Scott also got "*away with a lot more because of his scars,*" potentially explained by the guilt his parents felt, as well as them being at a point in their lives where "*they were very much wrapped in their own stuff all the time.*" Both the maternal and paternal grandparents treated the siblings the same. Oliver submits,

I saw my grandparents treat Scott like he was never burned and stuff, which pretty much was probably more their experience, because of the guilt my parents probably had about the whole incident. Even though it wasn't their fault, it was still probably hard on them I'd imagine.

When it came to learning his brother had been injured, Oliver states, "*Nobody talked to me about it,*" adding, "*Pretty much, they didn't communicate really well, my family. They were great pretenders like everything was okay all the time.*" His limited explanation was, "*Oh, he was burned by hot water.*" He assumes, *"They just felt like I didn't really need to know too much,*" but remembers having questions and that "*the adults were not comfortable talking about it.*" So, it remained a topic that was not open for conversation. He illustrates this in the following account,

I remember one incident where he came home from the hospital and he had had plugs put in his head, the hair transplants, and he came back and his head was all bandaged and I was five, so he was three, probably. I remember my mom being in the garage doing laundry and I walked into the kitchen and he had removed all of his bandages and I just freaked out. I totally freaked out because his head was all bloody with all these little [hair] plugs everywhere and stuff. I can remember going in my room and hiding in the closet. I wouldn't come out. Yeah. Then, I remember nobody really talking to me about it, which was weird. There wasn't a lot of communication.

Even at his grandparents, "*It was always just play and have fun and pretend everything's fine…It was a good place to be, because it was a safe place. Nobody was fighting or anything. They were just always fun with us…and loving.*"

Oliver felt he "*never really fit*" into his family as a kid because unlike everyone else he wanted to communicate all the time. He also recalls being a happy child and therefore questioned, "*What's the matter with you? Why are you so positive all the time? Why are you so happy all the time? What's your problem?*" His parents employed the stork explanation for how babies came into families, so he thought, "*Wow, they must have really dropped me in the wrong house.*" Communication is something Oliver finds significant for families to embrace. He advises,

> *I think that it's important to discuss with kids what's going on, to tell them so that they're up and they don't have to guess and wonder and all those things. It's important to be really open with them. I remember as a kid thinking, "Well, why don't they just tell me stuff? Why won't they just talk to me about it?"*

Oliver experienced the same recurring nightmare in childhood adding, "*I never really talked to anybody about it, because of course nobody ever wanted to talk to anybody.*" He narrates it as follows,

> *I used to have this nightmare that I was at my grandmother's house, my dad walked up to the door and then they always, my grandmother was afraid so she always locked her door…so he had to ring the doorbell and so in my dream my dad is holding my brother, he has his bandages and somebody opens the door and then an ax comes out and starts chopping my brother.*

Reflecting back now, he wonders if the nightmares were related to the lack of communication he received from his family and a product of how confused he felt about what was going on.

For a number of years, the experience relating to what happened to his brother were all he knew. Oliver elucidates,

[I]t's a weird situation when you have a sibling and you're that young [and have] that happen to you because you don't realize that everybody's not going through that stuff. You think it's kind of normal…It's like there's a lot of confusion when you're really young like that. You don't know if that happens in every family…Because we were so young, I really didn't see his scars so I grew up not really seeing them too much until he would go for a surgery or something. I notice[d] when other people looked at him more, but myself I didn't really—he was just my brother, so I didn't see the scars. It was strange.

Once Oliver got to school, he reports an altered awareness commenting, "*That's when I totally learned. I was pretty isolated before that.*" Specifically, making friends and learning about their family situations he realized, "*Oh, this isn't something that happens normally. This is a very different situation.*" Once he became conscious of the difference he acknowledges,

[T]hen pretty much what happens to you as a kid is you feel a little bit guilty, because there's nothing wrong with you physically as far as you're not scarred. When somebody tells you you're attractive or something, you go, "Oh no, don't be telling me that." That kind of stuff, yeah. So there is a whole thing because when you're a little kid and your sibling or somebody that you're that close to has visible scars that society sees them as different or flawed or something, there is a certain guilt that happens to the kids that aren't [burned/scarred] in the family.

Oliver describes that he "*cring[ed] at that stuff [positive feedback] when I was a little kid.*"

Since Oliver and Scott are almost two years apart, they had some overlapping years in school. He recalls,

I was pretty insecure and shy, and he was pretty much teased and bullied and all that kind of stuff, yeah. Because I was insecure and shy, I couldn't really do much to help him

or stick up for him or stuff like that, yeah. It was awkward. School was very awkward. It

wasn't a good experience.

He describes an incident when he and Scott were in eighth and sixth grade, respectively,

[Scott] had had a surgery and he had a stocking cap covering his head. I can remember a

bunch of kids cornering him and trying to pull all his stuff off and feeling really helpless

like I couldn't do anything to help him…Because I was too insecure dealing with my own

stuff back then…I guess what happens is that, I haven't really thought about it, but

probably if I would have been in a healthier family that communicated better, I might

have been stronger to help him…but I felt pretty disempowered, yeah, a lot of times and

powerless… I think we were all in survival mode at that moment in our lives.

Oliver proposes that survival beyond his brother's burn injury related to the overall

family dynamics, including their dad's alcoholism and verbal abuse. He notes, "*My parents don't*

remember any of it. It's like they've conveniently just put all that stuff out of their minds like it

never happened…My brother has chosen to forget a lot of it as well." Oliver does not remember

his dad drinking much before his brother's burn injury but declares with certainty his dad's

alcoholism would have occurred regardless stressing, *"[I]t would have happened. His father died*

of alcoholism and his mother drank…it was totally in the family. It's a disease in the family."

Oliver defines his relationship with Scott in childhood as "*really normal,"* adding, "*[W]e*

fought sometimes like siblings do, but mostly we were both really creative people, so we did a lot

of art together and a lot of building things and a lot of creative stuff." As a child Oliver recalls,

"*[I] just want[ed] people to stop staring at him and want[ed] people to just—I wanted for him*

not to be burned…As far as my relationship with him, I don't think that the burn affected it."

When they got older though, there was a shift in their relationship. For the first five years of Oliver's life, he remembers his parents as being very much in love; however, when Oliver was 9 years old their parents' marriage became characterized by daily discord. The family also relocated to another home, which he details as the catalyst for when everything became "*just a big mess.*"

Their parents divorced two years later, which was initiated by their mom. Oliver discloses, "*My dad was drinking really heavy. I would say he drank pretty much from the age when I was five years old, he started drinking quite a bit really heavy….his alcoholism became really bad.*" Scott would have been three at the time Oliver references the onset of his dad's heavy drinking and suspects that is all his brother knows of his dad; while, Oliver has memories of his dad before the drinking. Interestingly, he asserts,

> *[A]ll three of us [siblings] have a different childhood experience. My sister says she doesn't remember anything. My brother, what he does remember, he doesn't want to talk to me about…or he, at this time in our lives, he's kind of created a whole other version of it or something, which is fine. Whatever he has to do.*

After his parents divorced, Oliver and his mom experienced a challenging time in their relationship, which resulted in him moving to live with his dad, leaving his brother and sister with their mom. Oliver suggests this was the impetus for his altered and now strained relationship with Scott. He indicates they did have therapy as kids after their parents divorced "*and it kind of came out that he thought I abandoned him or whatever. That was why he was mad at me and all that stuff.*"

As far as the family at present, Oliver communicates,

I feel like I'm in a really good place with everybody in my family now. I feel like things
are pretty good, as far as communication and stuff. My parents are older now, so they're
much more softer [sic] and mellow now that they're older. They both were like warriors,
so they've lost a lot of that tough crust…that fighting mind kind of thing.

When he got older, he asked his mom why she never talked to him about Scott's injury and she replied, "*You were young, and we didn't want to upset you.*" His current understanding about the incident is still being pieced together through the storytelling he overhears amongst family members, primarily his dad or brother because his mom refrains from discussing those painful parts of their family history.

He shares his dad has been open with him and told him about 10 years ago that Oliver did a good job raising him. Oliver explains, "*That's kind of like [how] our relationship was always…he didn't really want to have kids…He was like a kid himself raising kids. My mom was really young.*" Oliver clarifies that his parents lived during a time where once a pregnancy is discovered it is followed by either marriage or adoption. He disclosed his mom had another child before he was born that she wanted to keep; however, "*[H]er parents sent her to a convent for pregnant girls,*" where the baby was later adopted, and it was never spoken of again. Oliver understands how damaging that experience was for her and shares, *"[N]ow, later in life, her and I have talked about it a lot and [how] it affected us growing up, all those things that were never allowed to be spoken about, yeah, and affected relationships and stuff like that.*"

Though the family experienced challenges related to various dynamics, Oliver highlights, "*I believe that all of my family has a little more compassion because of my brother being burned,*" adding a shared sense of mindfulness to people who have scars or something that

makes them different. He admires his brother professing, "[*H]e is just amazing, all the people that he touches and helps…He affects a lot of people in many ways.*"

Oliver accepts people may have considered him difficult as a child because he was so autonomous, but concludes,

> *I'm a pretty happy person overall…I try to have great connections with people and leave things good with people and…with my family, they've taught me to start over. You just start over with people, just like reboot, yeah. As far as my life, I love my life, where I live and everything. The world I've created is amazing. I always was…even as a child, I was so independent…I struggled with people telling me what to do because they weren't very happy, the ones telling me, so I did my own thing always.*

At an early age he began practicing mediation to help manage his thoughts. Oliver explains his parents "*taught me a lot what not to do,*" reiterating, "*[T]hey really are good people, but I always felt a little different from most of them, so it was okay for me and I celebrated that.*" Oliver accepts, *"[I]n my family, every one of us remembers those years as totally different,*" and this account was his. He concludes, "*I guess the main thing is that, through everything, people just have to be kind to each other. A lot of people just forget that, yeah. It can change a whole situation.*"

Artifact. Oliver provided two photos (see Figure 3 and Figure 4) from childhood of him and Scott as artifacts. He notes he selected these in particular because, "*[W]e were very close when we were little. We were best friends, so we did everything together.*" The first photo (Figure 3) is of the two of them playing in a river, which offered canoes and other activities, near where their grandparents used to live. The second photo (Figure 4) is of the two of them playing in a sandbox at their other grandparents' house. Oliver chronicles they spent a lot of time with

both their maternal and paternal grandparents growing up. In both photos Oliver points out that Scott is the one with the hat on, noting that after his injury it was critical for him to avoid getting the sun on his skin. He remarks, "*He always had to wear hats over where his head was burned and his face…he went through many surgeries, skin release, all that stuff. He always was covered up and everything.*" Aside from representing the closeness to his brother, he offers the photos as an illustration of how he felt like he was "*always being protective of him and watching over him and stuff.*" He details his experience in childhood sensing, "*[N]obody was really watching us…[so] when I was there, I was always feeling protective of him.*"

Ursala

It was early, around 7:30 a.m., one summer morning just three days into their traditional weeklong camping trip with several other family friends. Ursala, 10 years old, and her two sisters Ruth and Rose, 7 and 12 years old respectively, shared a large tent with their parents. Everyone else at camp was still asleep, but Ruth and Rose woke up and decided they wanted to get the fire going to make hot chocolate or something of the liking. Ursala states,

> *They went to go start the fire, and instead of dumping just some lighter fluid or fire starter fluid in there, they grabbed the wrong can and put gas in there, once they'd already started the fire, so it blew up.*

Ursala recalls, "*I woke up to the screaming. That was the first thing that I woke up to, was just hearing the screaming.*" She remembers how her parents, as well as other members of the camping trip, ran out of their tents. She stood with one of the other women and watched as her dad grabbed sleeping bags and blankets and rolled her sisters in them struggling to put the flames out, which resulted in burns to his own hands. Ursala remained at a distance, recognizing Ruth's clothes were burned to her body, but did not see her up close before they took her away.

Due to their isolated location, her parents did not feel there was time to call an ambulance *"so they just put 'em in the back of the car and drove to the closest hospital.*" They were later airlifted to another facility.

In the moments following the incident, Ursala remembers thinking, "*Oh, my gosh. What is going on?*" She said,

> *It seemed like it went by really fast because, obviously, they were burning and so my dad was working as quickly as he could. It did not seem in slow motion at all. It seemed very quick. By the time they got the flames out and were gonna take 'em off, I would say—it feels like in my head like it was only about half-hour, 40 minutes it all took place.*

Less than an hour after those initial screams, Ursala's parents were gone with both her sisters while she stayed at the campground with one of the other families to pack up the site. Then they drove her to her neighbor's house—five or six doors down—who had a friend her age, where she stayed for several weeks while her parents remained at the hospital. Ursala was grateful she remained asleep and did not get up with her sisters that morning to start the fire, understanding she could have also been severely injured, adding she felt "*lucky that that's the way it fell that day.*"

The information Ursala received from her parents was fairly limited; though she did talk on the phone with them the night of the incident. They told her she would need to stay with her friend's family for a while and disclosed, "*They're working on your sisters, and it's bad. We don't know if Ruth's gonna make it, but they're doing all they can.*" She acknowledges, "*That was really, really scary.*" She talked to her parents on the phone almost daily for updates, but adds, "*I wasn't able to talk to my sisters about what was really going on. I was kept in the dark a bit. [My parents] didn't tell me how much they were burned or what was really going on.*"

Ursala later learned that Ruth sustained burns to 65% of her body including her face, legs, and part of her torso. Rose sustained burns to 30% her body, which is confined to her legs, and Ursala admits, "*I often forget that she's burned because she's not as visual… When she's wearin' long pants, you can't really tell she's a burn survivor.*" Ruth remained in the hospital for six months and Rose was discharged home after about a month.

During her sisters' hospitalization Ursala remained with the neighbors for about two weeks and remembers asking her parents, "*When can I come home? When can I come home?*" She wanted desperately to go home and also discovered,

> *[T]he family was very, very religious. I didn't know how religious until I lived with them for a couple weeks. The mom was kind of strange. She would walk around the house telling Satan to get out of the room and things like that. I'm like, "Oh, my God. I gotta get out of here." Stuff like that just made me feel really uncomfortable.*

Ursala's wish was answered after a couple of weeks when Ruth's condition stabilized and her dad returned to his job as an engineer; thus, allowing her to return home as well. Her parents fell into a schedule and her mom—who was not working at the time—would stay at the hospital until her dad came to visit after work. She accepts,

> *My parents did the best they could under the circumstances. I knew that they had to do what they were doing to help her and that I could pretty much survive with the way things were until she could get better and come home.*

Rose discharged home before Ursala was ever able to visit her in the hospital and did not require any additional surgeries. Ursala was finally able to see Ruth in the hospital after a couple of months, which was welcomed after not talking to or seeing her for so long. She adds, "*[I]t was just weird with her gone and me not really being able to pick up the phone like we could*

today to talk to her." During her initial visits, Ursala remembers the hospital had not given Ruth a mirror to see the cosmetic changes from the fire and is unclear how long it was before she was shown the alterations to her face. She describes,

> *When they brought me that first time, I only got to talk to her through the curtain. They wouldn't even let me see her. I was just talking. We were both crying about the whole situation. I was just trying to get them to let me see her…. It was scary 'cause I didn't understand why I couldn't see her. I thought, "If I'm gonna eventually see her, what's gonna change between now and a month from now?" I didn't understand why I couldn't see her if I could talk to her through the curtain. I knew it was probably gonna be something shocking and that was probably [why] they didn't want her to see my reaction and just to be prepared for seeing her for the first time.*

She does not remember if Rose was there for that visit or not, but believes her parents were both there, one sitting on her side of the curtain and the other one on Ruth's side.

During the next visit, Ursala and Ruth were finally able to actually see each other after what "*seemed like a long time that [they] were apart,*" adding, *"[I]t was exciting to be able to see her.*" Rose was present as well. She details the hospital staff's warnings, "*She's not gonna look like she did before. She's got a burned face and burns to her hair,*" which she understood as their attempt to "*prepare [her] for what [she] was gonna see so [she] didn't go ballistic or make her feel worse.*" They again reminded her Ruth had not seen a mirror and Ursala discloses when she finally saw Ruth for the first time, "*[I]t was pretty shocking 'cause she didn't look anything like she had before she got burned. We both just started crying again.*" After finally being able to see Ruth, Ursala shares she thought,

"Oh, my gosh. I'm glad she survived," 'cause it looked like she went through something
horrible. I just remember thinking how strong she was, that she could live through that
and still be sitting there able to talk to me.

She details her intrigue at the time,

Mainly, it was curious questions, like "Are you hurting? Are you—how are you feeling?
Is there anything you want that we can bring for you?" It was mainly centered around
what happened and how she was doing.

Ruth was discharged not long after those visits and received ongoing medical treatment
and schooling in the home, making for a busy household. Ursala advised Ruth had a physical
therapist who was "*coming and going*" along with a daily tutor who "*became like a part of our*
family" and her mom—a trained nurse—"*doing the basic dressing changes and that kind of*
thing." She denies feeling like her parents neglected her, understanding the "*horror of the whole*
situation." She continues,

I felt lucky that I wasn't in that place and easily could've been had I got up early that
morning. There was a few times that I went, "Oh, it's all about Ruth." Maybe it wasn't
necessarily something to do with the burns, but later on it was still a lot about Ruth
because they were still trying to help her through the emotional part of what had
happened, even in later years. I never really had any kind of resentment or anything,
other than just thinking, when you're a kid, "Oh, I guess I'm the middle child, the
neglected one" or whatever.

At the time of the injuries, the sisters all attended the same elementary together. Due to
the incident occurring during summer, Rose did not miss as much school as Ruth, which ended
up being at least a year. During her recovery Ruth "*had to wear a mask for the pressure for quite*

some time when she was at home, and she didn't wanna have to go to school with the mask on;" thus, she had her tutor for almost a full year. Since Ruth was unable to return to school, Ursala fielded the questions saying, "*[E]veryone at school was asking me—I remember one of my teachers—the whole school knew what had happened. I just felt like everyone was lookin' at me like, 'Tell us what happened,' and 'How is she doing?'*" However, she appreciates the genuine act of support and caring from two of her teachers pulling her aside and asking, *"How are you doing? We know what happened…that your sisters were in pretty bad shape.*" They also advised her if she needed more time for assignments, or anything else, to let them know. Ursala assumes Rose's return to school, with concealed scarring to her upper and lower left leg that could be obscured by pants, resulted in fewer questions about her and more about her sister Ruth.

When Ruth did return to school Ursala asserts,

I was very protective. If anyone said anything and I was around, I would just—not physically attack, but try to get 'em away and say, "Don't say that. That's not nice"….I was just very protective, and if anyone said anything, I would get after them.

Ursala's sense of protection extended to the cabana the family belonged to as well when they went swimming and others noticed Ruth's scars. Ursala reports Rose was not receiving as many comments as her sister, though she did get picked on for wearing eyeglasses. She tells of a situation where, "*Someone threw 'em over the fence, and I went after and chased the people and got her glasses back,*" realizing, "*I guess I was protective of both for different reasons.*"

Ursala describes her family as one that is "*very close for the most part and have gotten along very well.*" Camping was a frequent activity the family did a couple of times a year. She fondly recounts, "*We'd always get to bring friends, so my dad would have these six girls 'cause there's three of us and we'd each have a friend on pretty much every trip…We did camping,*

fishing, hiking, and outdoorsy stuff." Once Ruth's health improved the family resumed their

camping trips a couple years later, though now they had a camper instead of a tent to sleep in.

The family never returned to the campground where her sisters were injured. Ursala affirms,

"*[T]hat would be too painful.*"

She describes a natural ebb and flow in the sisters' relationship that she suggests is based

more on their ages and interests than anything else. Before the campground incident, she

chronicles her and Rose were closer since they were only 18 months apart in age and Ruth was

about three and a half years younger than her, and almost five years younger than Rose.

However, after the burn injuries Ruth and Rose initially had more in common. Ursala speculates

that Ruth wanted to help Rose when she was older, but reports since Rose's injuries were hidden

to the general public and "*[s]he wasn't getting the comments, and she wasn't getting any kind of*

negative attention because of the burns…she felt like she didn't need any help." She furthers, "*I*

don't know that it necessarily brought them together as adults…'cause Rose is in denial. She's in

denial about anything that happened." Now, as the siblings aged, she feels that she and Ruth are

closer as a result of shared interests.

Ursala proposes the incident "*[D]efinitely shaped Ruth's whole life, right down to her*

career. If she'd never been burned, she probably wouldn't be in her position that she has now

and never would've become a nurse." Ruth initially went into business for about a year before

returning to school for nursing, where she maintains an extensive career—against her mom's

advice from her personal experience in nursing. Rose went to community college and has a job

in consumer relations. Ursala never planned to be a nurse, declaring her strong dislike for blood

and acknowledging she avoided witnessing any of her sister's care at home. Instead, she wanted

to be a teacher, but her mom was concerned about the pay, so she went into business and later

banking; though, she playfully admits, "*I should've just been a teacher. I'd have my summer off.*" Ursala surmises,

> I think we've all moved on, knowing that everything turned out okay and that she was
> able to live a very, very successful life. No, we don't dwell on it at all anymore. It's funny,
> 'cause I have a wine-stain birthmark on my arm, and I've had it since I was a baby. It
> covers pretty much my whole arm. I was telling Ruth, "Gosh, everybody's just always
> asking, 'Oh, my god, what happened to your arm?'" I go, "How do you deal with people
> asking?"

Resources provided to Ursala and her family were fairly limited; however, she acknowledges the hospital staff were supportive and furthers, "*Ruth became very close with a lot of the nurses that took care of her for all those months every time she was in and out of the hospital.*" The sisters saw a hospital psychologist a few times but "*all agreed it wasn't that helpful;*" however, Ursala recognizes, "*At that point in time, I don't think there was a lot in place to support.*" Ursala recalls one-time Rose commented, "*It's my fault. I feel horrible. I mistook the gas,*" but adds, "*[W]e never talked about it again.*" She wishes Rose received more counseling to work through her feelings and remarks,

> I think she's been skipped over a bit in some of the counseling and getting over guilt that
> maybe she might feel for having put the gas in the fire in the first place and getting it
> confused. I know that she had a lot guilt.

Reflecting back on her own experience she recommends more consideration for support "*as a family,*" concluding,

> Maybe that's part of why Rose got neglected, is because all the attention was on Ruth and
> her more serious burns. Other than that counselor, which didn't help, it seems like there

should've been something we could do as a family, letting us really know more about

Ruth's care and what she needed and her emotional state and how we could help. I think

that some kind of family group activity or group counseling or something like that

would've been more helpful so we could go as a group—as a family….More

communication would've been better.

Granted it was a horrific situation for a family to endure, in closing Ursala's relates,

[*W*]*hat maybe I can take away is that everyone is a lot stronger than they think they are*

because I'm sure when it first happened, we thought, "What is gonna become of us?" or

"What's gonna become of [Ruth] for having to endure all of that?" Just the strength that

came out of her is an inspiration, I think, to everyone that she meets, that she could turn

around and make a horrible situation into a great life. Probably just overcoming all of

that and the strength that it provides.

Emma

Emma, 5 years old, and her sister Isabella, 18 months old, were outside playing in the

yard while her parents waited on foster care services to make the final home visit to approve

them becoming foster parents. The family's home set up on a small hill and just below, where it

began to level out, there was a small ditch with rocks and a bridge overhead. Their parents had

worked in the yard the day before and burned leaves in the ditch—an area farthest removed from

any trees—and afterwards hosed down the ashes. It was now 24 hours later, and the girls found

themselves playing on the hill—Emma on a tricycle and Isabella in a wagon—while their parents

presumed the nearby ashes had cooled. Emma recalls,

I went down the hill first on the tricycle, and then she followed me on the wagon. Then we

got to the bottom of the hill. She got out of the wagon. I started pushing the tricycle up

the hill. Then I guess I was gonna go back down and get the wagon, cause she's not big enough to do it…The next thing I know is you just hear this awful scream. It's not like a normal scream either. It's like the kind of scream you hear when someone's murdering you. It's terrifying in every aspect. It's heart-wrenching and unbearable. All you hear is this scream. Then you look over, and you see her, that she's fallen, and you don't really know what's going on.

Emma's dad raced down the hill, picked her up, ran back up the hill and called 911. She details, "*At that point her legs were black,*" noting she's not sure if this knowledge is from her own memory or later seeing pictures of the injuries. Once Isabella was taken to the hospital, she was transported via helicopter to a burn center that was about an hour and a half from their home.

Isabella's scream is what Emma remembers most from the incident, adding,

It's haunted me for years, and I didn't even know it… [T]here was that time when I was at work and the little girl started screaming over a crayon, and I just burst into tears because it was that same scream. It wasn't dignified. Once you've heard that scream in a dignified manner, then you hear it for something ridiculous, you don't have the same patience. It's not the same. I burst into tears when the little girl screamed just because it brought back all those memories, and I didn't even know it was something I remembered.

Emma reports even at present when she hears kids cry, described by her as a "*distinct sound,*" it brings back memories and she regresses to that moment at 5 years old. She clarifies,

It's not so much every cry either, cause if it was every cry, that'd be awful… It's certain cries and the way that they cry….Yes, it comes back to me. I'm not gonna say often because it's not super often, but on occasion it does come back to me where I remember all of it.

Emma acknowledges her memory is spotty, arguing it could be because she was so young or because she was away from her parents for a sizable time frame and she chose not to remember. However, she asserts, "*I definitely remember the incident.*" After her dad got her sister up with hill she reports, "*The next thing I remember is being at the neighbor's house. A neighbor that my parents didn't really know very well, by the way. Just a neighbor across the street.*" The neighbor had a daughter who was a few years older than Emma who she recalls she played with by the coffee table in their living room.

Her next memory is being at her grandmother's house. During Isabella's six-week hospitalization Emma remembers staying with her grandparents—maternal primarily—and her parents stayed at a Ronald McDonald House near the burn center. She adds, "*They were gone the whole six weeks. I may have saw [sic] them once or twice. I don't remember seeing them at all.*" At the time, Emma recalls understanding that her sister "*was hurt, very hurt, because it was to a point where at one point they didn't know if she was ever gonna be able to walk again.*" She presumes that information was ascertained by overhearing discussions regarding the gravity of the situation.

Isabella endured subsequent surgeries and Emma reports, "*I think that on the day of the surgeries, I would stay with grandparents. Then after that, one parent would always come home to stay the night with me, at least when things were well.*" Unless the surgery was required to take place farther from home, and then her parents could be gone for a week or longer and she would stay with family. Emma expresses gratitude for the charity that housed her parents so frequently remarking, "*The Ronald McDonald House has impacted our family hugely. I have nothing but—I have never stayed there personally, but I have nothing but positive things to say about them.*" Emma's next recollection is seeing her sister in the hospital refusing to eat the

McDonald's french fries her parents brought and her sister getting a feeding tube, though she's unsure if she already had a feeding tube or got one soon after that visit.

After the hospital visit, her memories jump to Isabella receiving physical therapy at home. Isabella received physical therapy in an outpatient setting once or twice a week; but there were also daily exercises required at home her mom would manage, along with dressing changes. In Emma's memories, these activities are all grouped together. She recounts,

> *Again, with the screaming. That's basically the main thing I remember, is I remember she had… purple pressure garments. I think she had a pink one, too. They were on her hand and her legs. Then I remember my mom would take them off to do the stretches. At least I think she took 'em off to do the stretches. I would go in my room and turn the TV up as loud as I could and try to zone her out as much as I could, but all I can remember is the screams. I don't remember what I was watching. I just remember the screams.*

Emma denies a specific conversation explaining the medical care her sister received at home, assuming,

> *I knew it had to be done, and I knew that it was because if they didn't do it… She wouldn't be able to stretch her fingers out. She wouldn't be able to bend her toes. I knew that if they didn't do the physical therapy, she wouldn't be able to do things like that, but it was hard on me cause I knew she didn't understand. In that aspect, I think that I did kind of understand why, at least as much as a 5-year-old can.*

Emma conveys her response to the situation then was laughter. She explicates,

> *It wasn't because I thought it was funny. It was because I didn't know how else to handle it….Laughing was a coping mechanism for me, and I know that was hard on them. My mom knew it was a coping mechanism, but my sister [didn't] understand that. She's, at*

this point, two years old, and I'm laughing at her while she's screaming and crying. She doesn't remember that, thankfully, but I remember mostly the screams.

Emma fast forwards to a conversation she had with her dad when she was about 8 years old as her "*next most important memory.*" They were outside walking around the yard discussing Isabella's incident. Emma asked her dad, "*Why don't you go to church anymore, and why does our grandma come and pick us up and take us?*" She reports prior to her sister's injury the entire family attended church together but notes afterwards both her parents stopped and it was just her and Isabella who would go with their grandmother. Her dad told her that Isabella's injury made him lose his faith, adding he questioned, "*[I]f there is a God, why would God let something like this happen to such an innocent little child?*" Emma shares,

> *That stuck with me and still has to this day. It's part of the reason that I've questioned my faith, is because, yes, if there is a God, why? Why her? Why such a small child? Just why? I think that's the most important conversation that I've ever had with my dad in regards to Isabella's injury. It also went into his guilt. He talked about his guilt at that point, because, again, I was a little older, so I understood a little bit more what guilt meant.*

Her dad felt guilty for his daughter's injury in general, but moreover for not hosing her legs off with cold water because they would later learn from doctors that could have prevented further injury.

Aside from understanding her dad's guilt, she also realized how it affected her parents. She explains, *"[U]p until then it was just how it affected me and her. At that point, I realized, 'Oh, it's not just me and her. It's everybody. It's our family. It's the neighbors. It's the community. Everybody's affected.'"* Emma reiterates the importance of this conversation with her dad,

saying, "*I think about [it] all the time.*" She denies revisiting it with him in much detail since, or, plans to at some point in the future, stating, "*I feel like there's not much more that needs to be discussed on it, cause he feels the way he feels.*" She adds,

> *I know [his position] hasn't changed because there have been moments where I'd be talking to him—he would go to church once in a while with my mom, and I'd ask him, "Why, if you don't believe?" He would say things along the lines of "Just to make her more comfortable."*

Emma describes her mom's church attendance since the incident as intermittent, suggesting,

> *She goes through phases where she wants to believe that there's something out there. She'll start going to church again, and she'll start to feel more devoted, like she's doing the right thing. Then it's almost like there's something that clicks, and it's more of an inconvenience for her, so she stops going again. They take years at a time between these phases. It's on and off again, on and off again, on and off again.*

Emma believes the phases are related to her mom's mental health, disclosing she was initially diagnosed with obsessive compulsive disorder about the time Emma was 4 years old and then a few years later diagnosed with bipolar disorder.

Currently her mom is an "*off stage*" with religion, which Emma finds difficult. She explains,

> [*H*]*aving a parent that can't make up their mind about whether or not they believe there's something makes it hard on me, or hard on the children as to, "Well, is there something?" Cause a lot of people have straightforward faith. They grew up and they go to church every single Sunday, and there's no question about it. Where with me, I've only*

been to church maybe one-fourth of the Sundays up until I was 12 and then at that point

they let me decide.

Presently she posits,

[T]here's no proof. I believe that there's something out there, but I don't believe that it's

anything that we could know about... I think that if you want to go to the better place

when you die, live a good life. Don't do things that are wrong, like don't go killing

people. Don't go stealing from people.

She affirms that her family's experience with her sister's injury definitely shaped her

religious/spiritual views revealing,

[I]f not just from the way my parents viewed it, it also changed the way I [think] about it,

too, because I've been through the same thing. If there is a God, an all-powerful being,

out there, why did he let this happen?

Family mealtimes were something Emma reflects on as an activity they used to do

together, sharing,

I remember we used to have family dinners at least a couple of nights a week where, as

we got older, that kind of diminished. I don't really know why we stopped. My mom used

to make dinner almost every night, and we'd sit at the table, and we'd talk, and we'd

throw rolls at each other. We had a good time being around each other, talking about our

days. And as me and Isabella got older, that definitely stopped.

Emma defines older as "*teenage years*" and is specific about it being this timeframe recounting

the ongoing challenges with her mom, both before and after Isabella's injury, adding, "*I had a*

really weird relationship with my mom. She was not stable. A lot of the time I was the mother

role and she kinda took on a child role….we were struggling over who was the mom." Emma

recalls when her mom was diagnosed with her mental illnesses relating,

> *[I]t was an explanation as to why my mom was like this, why my mom isn't like every*
>
> *other mom out there, why my mom isn't supportive…. I don't think I knew the impact that*
>
> *it would have on me, and I don't think I realized how big a difference it was, but I knew*
>
> *there was a difference.*

During school Emma and Isabella overlapped one year in elementary and one year in

high school. Due to the layout of the elementary school they did not see each other during the

day, and she denies memories from that time. However, once they got to high school Emma

remembers her sister "*got bullied a lot.*" She furthers,

> *I never really knew who did it. It was more along the lines of she'd come up to me and*
>
> *say, "Hey, Emma. How are you?" She'd bug me a little bit, but I never really thought*
>
> *much of it, and I really didn't do anything to help. If she was lonely, I'd stay with her and*
>
> *comfort her and everything, but I never really did anything to help her with the bullying*
>
> *or any of that.*

Aside from bullying, there was a myriad of questions, such as, "*What's wrong with her?*

What's on her legs? What happened?" Emma advises,

> *I was always open to answering [the questions], especially when I was older. When I was*
>
> *younger, it was annoying—or it wasn't so much annoying as it was it almost felt rude to*
>
> *ask. Then when I got older, it was more like I understood "They just wanna know.*
>
> *They're just curious. She is different."*

She recognizes her comfort level with questioning likely originated from the passage of time,

noting,

[W]e'd been used to it cause this incident didn't happen when she was 14 or 15. This happened when she was very little, so her whole life has been dictated by this. And it's impacted our whole lives. It's just, it is what it is.

According to Emma, her relationship now with Isabella, "*[I]s a lot better than it used to be.*" She denies a memory of their rapport before the injury, but confirms they are currently in a more solid place, adding they talk to each other and hang out occasionally, such as birthdays or dinners out. When they were in high school Emma recollects,

I used to take her to dinner all the time. We had a good time with each other, and we still do. It's just there's only so much of her I can take because she's got a very loud personality…Sometimes it gets to be too much.

Emma verbalizes, "*I think [her personality is] something she was born with, too. I don't think that's something that the burns have impacted at all. I think she was born with it, and that's just her.*"

After the injury Emma admits, "*I resented her for a very, very long time… She got all the attention.*" When Isabella was 7 years old Emma recalls her going through a phase where she wore black lipstick and dressed in all black clothes with holes in her jeans. She states Isabella hated their mom and wanted to harm herself. Emma describes,

She scared us all. It was like she demanded all the attention all the time. My friends were always like, "Oh, Isabella. Oh, Isabella," and I hated it. I hated every second of it. It got to a point where I couldn't stand her. I remember dragging her out of my—cause she wouldn't leave me alone. I remember dragging her by the ankles out of my room and then locking the door behind me. I didn't do that once. I did that hundreds of times because she would never leave me alone. She always wanted to be around me, and I never wanted

to be around her. I don't—until I was older, I didn't realize the impact that that would

have on a child, but I don't think she ever will realize the impact that she had on me and

how much I hated her. I know hate is a strong word, but I hated her growing up. I wanted

nothing to do with her.

Yet, Emma confides a memory of a tender moment when Isabella was 10 years old and being admitted to the hospital for her self-harming behaviors. Emma narrates,

[W]hile she was being admitted, I'm reading her a book…It's some children's book, and

I'm trying to read it to her without bursting into tears…"It wasn't fair. Why did she have

to feel that way? She's been through so much. Why does she—why is her body doing this

to her? Why couldn't it be me that is having this mental breakdown?" That was the

thought that crossed my mind a lot growing up, is "Why couldn't it have been me?" That

was injured instead of her. Cause I was older. I would've understood a little bit better

why Mom and Daddy are hurting me.

Guilt is an emotion she grapples with and explains ambivalently,

I don't anymore, but I did for a while. I don't think I did right when it happened cause I

didn't really understand guilt, but as I got a little bit older, it was "Why didn't I go down

that side of that hill? Why didn't I make sure she was—why didn't I help her get out of the

wagon and take her wagon up first and help her up the hill instead of taking my tricycle

up first?"…[I]t was a whole lot of "What if's" and "Why didn't I do this?" more so than

it was guilt over—it wasn't so much that I felt that I caused it…it was more things that I

could've done differently to make it less prominent or to have hurt me instead of her.

Emma's relationship with her mom was often enveloped in adversity. Emma reiterates,

[M]y mom wasn't the mom. She was more of a child in aspects. Then there's my dad

being the only adult around, and all of his attention goes toward my mom and my sister

because I was there and could take care of myself.

The attention that Isabella required as a result of her injury maxed out her mom, which would

result in her dad taking care of her mom. Emma asserts,

I know some parents say that they try to give equal attention to their kids, but there was

no equal attention here. It's something I've forgiven them for, and it's something that I've

moved on from and we've moved on from as a family, but for several years I hated all of

them.

Emma denies her feelings were initially known to her parents, but advances,

I started to get depressed, and they put me in therapy, and it came out that I hated them. I

hated all of them. I think they started to realize how much that they had neglected—it

wasn't so much neglect as it was just that they didn't have time for me…which I

understand now, but I didn't then.

She assumes her mom feels her own guilt, commenting, "*She's the mom. She's supposed*

to take care of everybody, but she's never expressed it to me. I know she feels guilty about other

things, like the way that I grew up and stuff like that." She suggests,

You can see it in her face when we talk about it. In the past when I've told her that I

resented her, when I told her that I, quite frankly, hated her, you could see it in her face.

You could see it in her expression. She's very easy to read. You could see how much it

pained her to hear that and for her to hear that it's her fault that I was feeling the way I

was, at least somewhat.

Emma clarifies that the hardships with her mom are not easily disentangled, "*I think if Isabella*

had never been injured, there still would've been resentment, but I feel like if…Isabella was still

injured, but there was no mental illness, it still would have happened. The resentment still would

be there."

Emma discloses her own history with mental illness, specifically self-harm, suicidal ideation, anxiety, depression, and bipolar disorder. She began attending therapy off and on when she was six and was last hospitalized at the age of 15 or 16. She speculates,

I think the reason it was the last [hospitalization] is because I really started to open up about things that had been going on and was able to move past them. By that, I mean I told my mom that I resented her. I told my sister that I resented her and finally opened up about how I was actually feeling. It allowed me to actually utilize the coping skills they taught you and move forward. It has not been an easy road, moving through all of this. I know part of it is because I am also bipolar, but I can't blame all of the issues I've had growing up on being bipolar…I've not had an easy childhood.

She chronicles the family began counseling "*around the time that Isabella had her meltdowns. Then a few years later I had my meltdowns, and all the while my mom's, every three or four years, having meltdowns and in and out of the hospital.*" Emma remembers a very real fear of coming home to find her mom "*in the bathtub, dead, from slitting her wrists or something,*" adding, "*I grew up afraid that she was gonna hurt herself all the time.*" She illustrates,

I remember one time…I was probably 16 at the time. I was in the basement, and I found her down there banging her head on the concrete floor, pulling her hair out, talking about Isabella. She blacked out. She doesn't remember this. She thought Isabella was dead. We had to actually get Isabella down there to show her that "She's not dead. She's

here,"…I had to call my dad home from work. I was always having to call him because my mom was having mental breakdowns.

In terms of her parent's relationship Emma's articulates, "*My dad was my mom's rock, but my dad was also my mom's puppy dog. He did everything that she asked, everything she wanted, and I kind of hated that.*" At the time she wanted her dad to stand up to her mom, but concedes as she got older, she began to understand his actions more; still, she recounts two different times her parents contemplated divorcing when she was a teenager. She reasons,

My dad had been the rock for so long, and I think that at some points he just got tired of being the only one that could stand his own…cause he's the only one of us who's not had a mental breakdown and just crumbled, and I think that's hard on him….[H]e sees a therapist regularly. At least he used to. I don't know if he still does. It's been very hard on him because, like I said, my mom's not always been the mom. He's basically been [running] a single-parent household with three children.

In addition to the services offered from the Ronald McDonald House, Isabella began attending burn camp when she was around 7 or 8 years old. Emma recalls participating in some family day events associated with the program as well. She denies feeling jealous of her sister attending burn camp, stating that she was old enough to understand why her sister got to go and she did not. She furthers, "*I didn't see it as a privilege for her to get to go. I saw it as a 'She earned it.'*" Though when asked about uninjured siblings having an opportunity to join summer camp she also admits,

I think it's really important that they come or that they at least know about it and have the opportunity because, growing up, I never had friends who had siblings that were burned. None of my friends understood…. I think it's important that you can make connections

with people who understand, who've been through similar things. If that's the only reason

for the camp at all, then that's reason enough.

She recognizes the added benefit to families by offering the programs at no cost, remarking, *"[A] lot of these families were drained. Surgery after surgery, you really do get drained."* Thought, she comments her families own financial experience was different,

My dad's always had a really good job. We had all kinds of people donate… [M]y dad

worked with this man who had a son who was about my age who started a fundraiser and

raised $3,000 to help…It was a big deal for the whole community when it happened, and

we had a lot of support from everybody.

Emma credits her experience in childhood for influencing her thoughts about a career but remains unclear the direction she will go. She details,

I've always wanted to do something with kids, be involved with kids, and I think part of it

has to do with, (a), I didn't really get a childhood, but, (b), I know kids. I know how to

interact with them, and I'm good at it. That's why I wanted to be a teacher, but then I got

into the program and I did not like what they were teaching….For a while, I also wanted

to be a therapist. I thought maybe I can help people the same way they've helped me, but

then I realized that I couldn't handle that. I couldn't handle taking in other people's

problems on top of mine and balancing it all out. I just couldn't do it. Now I don't know

what I wanna do.

She recently married and is working for a major retail store in a job that allows autonomy, which she finds enjoyable.

When asked to consider the most memorable thing in childhood Emma declares,

> *To be honest, I try not to remember my childhood…I don't have any pleasant*
>
> *memories…Not any that trump the bad. There was never enough good to trump the bad*
>
> *to make me wanna remember it…I don't bury them, and I'm willing to talk about 'em. It's*
>
> *not an issue. It's just when you ask me if I had any good childhood memories—maybe I*
>
> *went to the beach a couple of times. That was fun probably, but there was so much bad*
>
> *that happened that it just trumps it out and I don't remember…Which sucks.*

While her childhood was challenging, Emma acknowledges,

> *I have moved past a lot of the troubles that I've been through. I'm doing so much better*
>
> *than I was when I was a teenager. I get along much better with my family. I don't resent*
>
> *them anymore, don't hate them anymore. They annoy me a little bit sometimes, but that's*
>
> *normal. I don't hate myself anymore, and I think that's the big one.*

The onset of Emma and Isabella's emerging relationship was marked by a major trauma; therefore, she ponders, "*If we'd had a foundation built, then this might be a whole different conversation, but I think because she was so little, we just never had that friendship built.*" Emma concludes,

> *I do not have a normal family. I don't think it's bad anymore. I used to think it was bad. I*
>
> *think that we're different, and we're different and that makes us unique. It has impacted*
>
> *who we turned out to be, but I don't think it's a bad thing anymore.*

Artifact. Emma selected an assignment from Isabella's Spanish class (see Figure 5) as her artifact to represent their relationship. She was 14 years old at the time she completed the assignment and Emma acknowledges, "*It was one of those basic things. You do it in kindergarten except it's in English.*" Isabella's task was to write about her hero. It reads,

My hero is my sister Emma. She is 17 years old. We are from [state] but we live in

[state]. She loves to work with kids, shop, and spend time with friends. My sister is nice

and friendly.

She says the paper is still hanging on the refrigerator in her parents' home almost five years later.

She explains, "*I feel like that represents our relationship because, in a way, she looks up to me,*

and in a way, I respect her for it. I respect her anyway, but you know what I mean."

Michael

The first part of Michael's story comes by way of accounts that have been shared with

him, not firsthand experience, since he was tucked safely in his mother's womb the day his 2-

year-old sister Irene was injured. Michael's dad was on his way to work one morning and

received a phone call from Irene's home daycare facility advising him there had been an

accident. He turned his car around as fast as he could headed back to the daycare. While en route

he got pulled over by the police for speeding. Thankfully, the officer let him go after Michael's

dad explained what happened.

When he arrived at the daycare, he discovered the ambulance was already there to take

Irene to the hospital. His dad learned she had gone into the bathroom alone—another point of

concern for his parents in addition to her burn injuries—and turned on the hot water to wash her

hands. Michael is unclear some of the specific details reporting,

I don't know how long she let it run or what exactly happened, but at some point, in there

she dunked her hands in the water. I don't know how hot the water was, but it was

enough to severely burn her hands, basically from about the wrist down….[S]he was

young enough to where she knew she was supposed to wash her hands and didn't

probably think to check how hot it was before she put her hands in there. I'm not sure if

the sink had filled up at all, if it was clogged or something and then she just dunked her

hands in the water.

The state had just come out to perform their inspection of the facility and either failed to check the water heater properly, or, failed to check it altogether, which later resulted in a lawsuit and subsequent financial settlement.

Irene was taken to a local burn center for treatment of the third degree burns to her hands. During her hospitalization, Michael was born in a different hospital. Once he and his mother were released, they went to the burn center where he sister was being treated. As told to Michael, his sister was excited to finally meet the little brother she had been so anxiously awaiting and exclaimed, "*My Michaely, my Michaely.*" Irene remained in the hospital for four to five weeks before being discharged where her recovery continued at home, as well as follow up appointments. Fortunately, Irene did not lose any of her fingers to the injury or subsequent infection; still, her fingernails experienced damage and she received skin grafts on her hands that required routine cleaning, which her dad performed. Although Michael does not remember these episodes, he recalls the following,

> *[M]y dad would tell me about how you know, he would have to go in and scrub her hands*
>
> *to keep 'em clean, and she hated my dad because she knew that he was coming in to you*
>
> *know…not purposely, but it was gonna be painful to clean her hands and obviously*
>
> *traumatizing for my dad too to see her like that.*

Although Michael is not aware from personal experience, his dad narrated stories to him, confiding how difficult it was for him to cause such excruciating pain that when his daughter saw him—her own dad—she would burst into tears. Michael empathizes with his dad stating, "*I can't imagine how hard that was for him to not wanna cause her any pain, but it had to be done, which*

is probably why it was his job…and not my mom's." Michael reports Irene "*hasn't had too much maintenance as far as post injury.*" There was talk of surgery once she got older to help increase her range of motion in between her pinky and ring finger; however, Irene was a division one athlete and after consulting with her doctor she decided against. Michael cites, "*[I]t would've been too long of a recovery and she would've been out, not been able to play basketball.*"

Michael's earliest memory of understanding his sister endured an injury came through interactions with neighborhood kids and school. He details Irene "*coming home upset and my parents had prepared her well enough to know that kids were going to say things and kids were going to make fun of her.*" Michael credits a burn camp as one of Irene's biggest sources of adapting to her injury. Additionally, he recognizes his parents—especially his realist dad—for blatantly telling her, "*There's gonna be people who are gonna say things and there's gonna be other kids who are gonna make fun of you.*" Therefore, Michael says he observed his sister return home following these incidents and "*it kinda was water off her back, but she would still bring it up because it bothered her.*" Yet at the end of the day, due to her attendance at burn camp and her seeing "*other kids who were injured far worse than she was, she never was 'woe is me.'*"

However, when Michael was around things sometimes went differently. He recollects,

> *[W]e had a couple kids that we'd be out just doing kid stuff, playing and they wouldn't let her play or they would say something about her hands looked funny and ended up in little brother getting in fights and trying to stand up for her 'cause she wasn't gonna say anything back to 'em. She was always strong enough to you know. It didn't really bother her, but it bothered me because it was my sister.*

Michael reports his dad is a "*pretty tough-nose guy,*" which he reasons is why his sister turned out as tough as she did. He adds he instilled the following in his two kids, "*[Y]ou two need to*

protect each other… if anybody messes with your brother, you better step in or if anybody messes with your sister, you better step in." Michael understood it to mean, "*[T]his is your family and if somebody doesn't treat them right, it's your responsibility to step in.*" He clarifies, "*It's not like we were out there, both of us, fighting.*"

The physical incidents occurred more when they were younger, because both kids began to play sports, which Michael thinks helped. He asserts,

> *[W]e were both very good athletes and she was a pretty imposing, just physical girl. She was six foot tall and she was built. She was really strong and so there wasn't—when she got older there wasn't a lot of people who said anything to her. A lot of people were more impressed by her and I think there was a lot of girls who feared her… because of how imposing she was, and she was a great athlete…I mean she was also a very kind, just person in general.*

From middle school and beyond Michael denies it being an issue anymore describing how focused on school and athletics she was, as well as being indifferent to other people's opinions of her.

Although thinking back on the day of Irene's injury is emotive, Michael notes, "*It was never hard to talk about as a family.*" He adds the topic was not off limits or taboo commenting, "*As far as the accident, this is why I feel I know, not to a tee, but I know exactly what happened to her.*" Nonetheless, the graphic images of Irene's injury were off limits until he was older. Around the time he finished high school Michael says, "*My mom finally pulled 'em out and let me look at the pictures of her burns.*" He denies specific memories from childhood inquiring why his sister's hands had a different appearance. Instead he suggests,

If I were to take my best guess at what happened, at a very young age, I probably at some

point did have that question and my parents were probably very honest with me. I

probably learned more and more as I got older…I can't specifically remember it, but I do

remember. There's been multiple, throughout my life, you know, sitting around the dinner

table or something as we grew up and just more and more questions started coming from

me probably.

When Michael and Irene were 2 and 4 years old, respectively, they moved from the area

where they lived when Irene was injured to a new neighborhood and remained there the rest of

Michael's childhood. It was here the family got introduced to burn camp. One of their neighbors

in the close-knit community was a firefighter and also volunteered each summer at the camp.

When he learned of Irene's injury, he invited her to the program. Michael's parents found

comfort in knowing he would be there, so they allowed Irene to attend.

From around six years old up until his seventh or eighth grade year of school, Michael

fondly remembers participating in a Family Day event with his parents at the camp, which

included having lunch with Irene and enjoying a variety of games (e.g. archery, bouncy house,

horseback riding). Unfortunately, the program came to an abrupt end as Michael recounts,

I remember one year they stopped doing it. There was no more family day and I always

loved going. I was a little kid. There was a ton of fun things to do. I guess the reasoning

was that it was hurtful…to some of those kids who didn't have families, or their families

couldn't come during the day. Especially for some of those kids who come from not the

best home life or best home situation. Their families wouldn't come, and they would have

to sit there all day and watch other people, happy families running around. I saw both

sides, but at the same time it was hard for me.

Irene attended the camp until she aged out of the program and continues to return—schedule permitting—as a volunteer now herself. Michael denies a time where he thought, "*I wanna go to camp with her.*" He considers it could be due to his early involvement in athletics asserting,

> *I probably had my own camp or my own—I had basketball practice, or I had something that I was doing that one of my parents was gonna be there for. It's not like they were just leaving me in the dust…I never felt left out in that aspect.*

Michael recognizes the value of camp stating, "*It definitely made a huge impact on her life. Not only her life, but our family's life,*" detailing, "*I think that it really sunk into her that there's other people who are in worse situations than she is, and I think it made her feel gracious. She would bring that back to our [family].*" He recalls his dad also volunteered at the camp program and later participated in a toy drive for the burn center where his daughter was treated, something Michaels relates as "*right up his alley.*"

Through the family's experience with his sister's injury and burn camp Michael developed an awareness of the struggles endured by others. He explains,

> *There's just so much abuse. There's a lot of abuse, which just blew my mind…My sister would come home with some of the most disturbing stories, which I think was part of the reason why we were always taught 'look how fortunate we are.' Or kids who were burned and then they're orphans, or they don't have a family, or when they were really young, they were abused and don't know how—there's kids who don't even know how they were burned.*

Though he knew from his sister's time at camp that individuals who experienced a burn injury want to "*be seen as normal people, because they are,*" Michael admits his own challenges managing interactions over the years. He describes,

> *I can remember when I was a young kid it was—you do shy away from the ones that are burned head to toe. It's such a traumatic thing, especially for a kid. I was really young too, right? My first time seeing a kid that didn't have any ears because he was burned so severely, I was put off by it. Obviously as the years went on it's just—it's such a difficult thing. Disfigurement is terrible. Nobody wants to be looked at or stared at.*

Again, his reiterates his family's mantra on being fortunate and finding blessings in life.

Irene was eventually awarded a pain and suffering settlement for her injuries. Once she turned 18 years old, she was able to collect the funds her parents set aside for her. Michael reports he knew little about it, "*It was more between them and my sister. My sister probably didn't even really know for a long time.*" He adds, *"If I know my parents as well as I know them, they probably didn't let her know any of that stuff until she was much older, until she was probably getting close to 18.*" Michael admits,

> *I never felt it was more of a—because we had such a good relationship—it was more of, I don't wanna say a joke, but it was lighthearted jealousy, you know what I mean? She turned 18 and got this big old sum of money and she got herself a new car and I was like, "Dang it," kinda thing, but it wasn't like I was angry or jealous of her, not like "She didn't even remember it. How she get money for this?"*

Michael again credits his parents, as well as his relationship with Irene, reiterating, "*I think my parents wanted us to be aware of how fortunate we were.*"

The family's relationship to date remains strong. Even though Irene's dad was put in the difficult position of providing necessary medical treatment to his daughter that also caused pain, Michael affirms,

> *My dad and my sister, I mean as far as I can remember they've always had a great relationship. I don't think that that played a role into anything as she grew up or got older…I mean she calls my dad just about every day.*

He goes on to say,

> *[My parents] have a great relationship with both of us, but…I think my sister is more attached to my dad and I think I'm more attached to my mom. It's not very lopsided. It's just how it goes. I think my sister is a daddy's girl and I'm a mama's boy.*

> Michael ponders the impact his sister's injury had on his life overall, even questioning,

> *[H]ow effective I would be [as a participant]. Other than these little things here and there, I don't really know if it made a huge impact on my life. Maybe it did more than I think it did, but I think that's a testament to my parents and her…Just the way that they handled it and I never felt she got special treatment. I never felt she was favored. I think my parents did a great job of handling both situations…Again, that might've been 'cause we were young. I don't know."*

He acknowledges his sister's injury was "*a soft spot for sure*" and says when his parents did discuss, "*[I]t didn't come without sadness because of course, no parent wants to see their child, their baby in that much pain.*" Still, they followed up with,

> *We're very fortunate…Yes, it sucks. It was a terrible accident, but aren't we fortunate for how we turned out? There's people in this world and people who are not only burned but injured or have worse experiences in their life.*

Michael declares this line of thinking "*rubbed off on my sister and I as we grew up*," concluding, "*I hate to say it's not a big deal, but we never looked at it as she has this terrible injury. We always looked at it more of look how fortunate we are.*"

While Michael questioned the utility in his story, when asked why he agreed to participate he humbly replies,

> *I just know that the people in the burn community have done nothing but good things for my sister and my family and I think I'm just a helpful person, that I don't mind helping as-is, but especially for people who are trying to do good for other people…and like I said, if my sister thinks it's a good cause and she asked me to do it, I'm probably gonna do it.*

Artifact. Michael provided two photos (see Figure 6 and Figure 7) as artifacts that symbolize his relationship with Irene—one from childhood and one more recent. He perceives these as illustrations of them then and now. He described the photo of them when they were younger (Figure 6) as imagery indicative of their foundation,

> *[W]hen I was an infant, she took care of me. Not that my parents didn't, but she always looked out for me whether it was sports or school, or she helped me with anything. She was the best big sister I could ask for.*

The recent photo (Figure 7) of them was taken on his sister's wedding day. He confides how much he likes the photo, explaining it demonstrates them now, "*I'm grown up and she's grown up and we're still best of friends.*" He advances, "*I just have always felt like she was always the strong one when we were younger, even though she was injured, and she was always the voice of reason.*" He discloses he had a lot of stress and anxiety in childhood. His sister is someone he

identifies as his "*best friend*" remarking, "*[S]ince I was a little kid it's just been her and I've always leaned on her for strength and stuff.*"

Metastory

After hearing detailed individual accounts for the seven participants, a metastory (Riessman, 1993), or synthesis, will be offered in the following section that explicates identified overarching themes—discussed in greater detail in the following chapter—across participant stories, as well as discrete distinctions that make the narratives unique.

Introduction

Incidents that result in burn injuries are often ensued by immediate chaos, which may include attempting to: physically locate individuals in the moments that follow; determine what happened; extinguish a fire; provide basic medical care; and/or contact emergency services for advanced medical treatment. Within a matter of seconds worlds are shattered. The incident becomes life-changing. Understandably, it becomes acutely altered for the individual who sustained the physical injury. However, a burn injury trauma for a child yields consequence beyond the physicality and impacts a family—specifically their uninjured siblings—in ways that have historically been overlooked. Therefore, this synthesis is provided for consideration in addition to the individual accounts.

Acute Incident/Hospitalization

Burns injuries characteristically involve a surprise factor that catches everyone off guard. As author Stewart O'Nan commented on their review of Barbara Ravage's book, *Burn Unit* (2004), "[E]ach of us is just a spark away from being a burn victim." The injuries do not discriminate leaving everyone equally susceptible to the anguish that can ensue. The four different etiologies of burn injuries—thermal, radiation, chemical, or electrical—are produced by

a vast array of circumstances. These may include but are not limited to house fires, car accidents, scalds, explosions, exposure to chemical agents, or lightning. Often, as was the sole case in this study, the injuries are due to accidents; yet, there may be circumstances where injuries occur as a result of abuse, neglect, or self-immolation.

Siblings who are present, and many times witnesses to the trauma, find their senses—visual, auditory, and olfactory—are often saturated with stimuli. Optically they absorb images that may include blistered dermis or charred and blackened flesh—sometimes down to the bone—or skin that appears dripping or melting. The sounds of screams, from pain and fear, can be haunting and often echo in the uninjured sibling's conscious and dreams. The smells of burning flesh and/or smoke can also be seared into the nose, again frequently resurrected while awake or asleep. Additionally, the physical trauma from the burn can be so horrific the injured sibling becomes unrecognizable and observers are faced to consider the wounds as potentially fatal, or at a minimum seemingly irreversible. At times, the uninjured siblings also witness injuries being sustained by more than one loved one, which often involves the individual attempting the rescue.

In the moments that follow the injury incident, the scene is typically enveloped in a flurry of activity from passersby who attempt to help and/or first responders, such as police, fire, and ambulances services. At this time, uninjured siblings find themselves being shuffled elsewhere to prevent further exposure to the scene and to ensure undivided focus can be placed on the child who sustained the injury. This may be a temporary relocation, or it may be prolonged. Moreover, the individuals they are placed in the care of while their parents remain with the injured sibling—or alternative caregivers—could be people known to the parents, such as other family or friends, or, they could be proximal options, which may result in uninjured siblings being under the care

of others unfamiliar to the family. Though they may be isolated incidences, it is possible for uninjured siblings to endure experiences during alternative caregiving that are physically or emotionally injurious to them.

Based on the severity of the injured siblings' wounds, it will likely be necessary for them to receive treatment at specialized facilities, or burn centers, which could add geographic stressors to the situation. Yet, irrespective of the treatment center location, parents usually stay at the hospital or nearby housing to remain accessible, particularly since in the early phases' prognosis can be speculative. This results in the uninjured siblings' experiencing extended periods of separation from both their sibling and their parents. In the case of multiple uninjured siblings, they may be separated from each other to prevent overextending the alternative caregivers. For parents who were also possibly injured at the same time as their child, and, dependent upon their injury, the treatment could occur at the same hospital or it may be different. Regardless, the uninjured siblings will likely endure lengthy separation, whether perceived or actual, from their parents and sibling as the incident culminates in disruption and disconnection. Moreover, alternative caregiving typically remains intact, whether it is assumed by family or friends, or remains the responsibility of those less familiar.

Siblings not present at the time of the injury will likely remain in the care of others delegated by their parents, until such time that the family can be reunited. Although these siblings did not bear witness to the incident or the immediate aftermath, they may still experience degrees of shock and confusion when initially seeing their injured siblings' cosmetic changes. Depending on the medical status/prognosis of their injured sibling, some uninjured siblings may be allowed brief encounters during the acute hospitalization. If they are allowed visitation, they may be taking in stimuli for the first time, or, revisiting the stimuli following the observed initial

incident. Either way, the experience can overwhelm their senses. Emotions often vacillate between worry, happiness, excitement, and distress. Furthermore, the communication they receive about what is transpiring before, during, or after the injury and/or visit can be as challenging to comprehend as the other alterations to their sibling.

Post Discharge/Ongoing Medical Treatment

Following the injured siblings discharge from the acute hospital setting, adjustments are necessary to manage the "new normal," which includes adaptations to how others engage (or disengage) with both the injured individual and their family. This almost certainly includes changed routines, interactions and roles. Due to their body's physical changes, injured siblings may require new consideration for how others are able to interact with them in terms of physical touch, activity restrictions, and reduced stamina. The injured sibling will likely require ongoing in-home and outpatient care. The ongoing care can involve the uninjured siblings bearing witness to their parents performing medical treatments—at times an activity siblings may also aid in— and/or it could also involve outsiders (e.g. allied health professionals) in the family's home to assist with treatments, which again are potentially observed by the uninjured siblings. Aside from in-home care, injured siblings will likely undergo subsequent medical care/surgeries, which may endure well into adulthood. This may also require a return to alternative caregiving for the uninjured sibling. Therefore, the permanency of nuanced routines and caregiving remains uncertain as injured siblings rotate in and out of the hospital and produce emotional fluctuations in their uninjured siblings within the transitional environment.

In addition to revised routines and relations, as well as uncertain caregiving roles, uninjured siblings may also find themselves fulfilling a protective capacity. This often includes managing the curiosity and cruelty of others by responding to the direct questioning and looks of

others, or, it could be, via the perceived indirect or disengaged behaviors of others. Depending on the context of the situation, uninjured siblings' defensive responses might be verbal or physical; however, they may also deem themselves defending their siblings by choosing to avoid interactions or activities. Lastly, uninjured siblings may also withhold their own emotions or refrain from conversations they fear will be hurtful as an attempt to shield their injured siblings.

Changed relations and dynamics are not only experienced outside of the family but are probable within also. Specifically, uninjured siblings often perceive both subtle and forthright differences in treatment by their parents. As noted above, parents are frequently physically separated from the home and family; but they can also seem absent even when unified in the same home again. This may be due to the strain they experience because of the demands required to tend to the injured sibling's physical needs; yet, it may also occur as they feel the need to provide enhanced emotional support to the injured sibling. Furthermore, the differential treatment and seeming detachment may be a consequence of their own emotional response, such as guilt, which they are trying to manage; though, for some uninjured siblings the reduced attention could come as a welcome reprieve if they prefer to exist more discreetly. Lastly, aside from attention, increased physical possessions for the injured sibling could become an alternate way differential treatment is experienced.

Ongoing Challenges

Burn injuries—especially those classified as major/severe—are usually not a one-off type of injury. Instead, as previously highlighted, these injures commonly require an ebb and flow of treatments, surgeries, and procedures, which for some are endured for years. Therefore, many of the experiences discussed above that occur during the acute incident/hospitalization and post discharge/ongoing medical treatment phases are not exclusive to just that time frame following

the initial injury and will often be revisited. The journey of healing and recovery, both physically and emotionally, is not linear and uninjured siblings are positioned to consider it as a cyclical phenomenon.

As such, this recurrent experiential aspect typically yields sustained considerations for the uninjured siblings in a number of areas. First, uninjured siblings revolving emotions commonly remain palpable from the onset of the injury. However, many emotions experience their own evolution over time and amidst maturation, with most uninjured siblings eventually embracing acceptance and understanding. These sentiments can include anger/frustration, confusion, depression, envy/jealousy, grief/loss, and guilt. They can be experienced with or towards others in response to stimuli, situations, and/or thoughts/feelings; but, they can also exist in isolation as uninjured siblings do not feel they have someone to share their feelings with, or, because their thoughts were dismissed, which resulted in them retreating.

Communication is another area with concerns following the acute injury that likely remains through hospitalization, aftercare, and community/family reintegration. Uninjured siblings often experience either nonexistent or indirect communication styles that may culminate in enhanced feelings of confusion, worry, or angst. There is often the absence of direct communication regarding the details of the physical injury. This could be due to overwhelmed parents who are themselves trying to comprehend the specifics, or, it could be because they are trying to gauge what or how much is appropriate to share. Additionally, uninjured siblings may find attempts at an emotional exchange that explores thoughts or feelings lacking, whether it is from them initiating the dialogue or waiting for others to do so.

Autobiographical Reasoning

Burn injuries are undoubtedly physically and emotionally grueling wounds to those who sustain the injury. However, uninjured siblings are likely to endure their own trauma, typically in solitude and silence. Yet, it is likely this journey will prompt an evolution of awareness and growth for uninjured siblings within the context of the self, relationships, and/or worldview. Although uninjured siblings will likely articulate adversity—in the past or present—many will counter by sharing knowledge acquisition or newfound meaning in life. This reflection is primarily quietly introspective with most denying a sense of collective belonging and support. Still, reflecting or engaging in conversation about their past experience suggests connections to their present and visualized future, which opens a window into their identity.

Conclusion

This metastory provided a fusion across uninjured siblings' stories to suggest a generalized experience, in addition to distinct characteristics that may not apply to all. The account offers multiple areas for consideration regarding the journey endured by uninjured siblings, which as illustrated extends long after the acute injury and quite possibly a lifetime. Though their injury is not physical, there is powerful evidence to suggest their often-overlooked narratives warrant further consideration within the context of the overall burn injury experience. Specific consideration is critical within the context of programs/services for the uninjured siblings that are part of a family system.

Chapter Summary

This chapter offered an exclusive opportunity to hear directly from uninjured siblings about various aspects of growing up with a sibling who experienced a burn injury in childhood. The artifacts provided visual data that added depth to our understanding as uninjured siblings

explained the significance of their meaning within the context of their sibling relationship. Through the participants' candor and vulnerability these detailed and nuanced stories allowed readers the chance to become closely acquainted with their accounts. To my knowledge, this is the first time their experience has been communicated this way to date in the literature. A metastory also outlined an archetypal description. The next chapter will highlight five themes that emerged across all stories, along with descriptions and supporting quotes.

CHAPTER 5

RESEARCH FINDINGS—THEMES

Introduction

Chapter 5 serves as the second analysis chapter employed to address the research

questions previously outlined. Detailed stories of each participant, as well brief explanations of

artifacts they felt represented their sibling relationship before, during, or after the burn injury,

and a metastory were provided in Chapter 4; therefore, this chapter will focus on a discussion of

the themes that were identified across individual experiences, or participant stories. Specifically,

the following five overarching themes will be reviewed: 1) separation and alternative caregiving,

2) altered interactions and ambivalent roles, 3) (r)evolving emotional pain, 4) communication

concerns, and 5) identity through autobiographical reasoning. Themes two through five include

sub-themes (i.e. codes that were organized within the primary overarching theme). These themes

and sub-themes facilitate further contextualization of growing up with a sibling who experienced

a burn injury in childhood; yet, they are not meant to dilute or reduce the nuances of uniquely

individual experiences. Instead, they are intended to capture key similarities or commonalities

between and amongst stories, recognizing participants may not encompass all aspects of the

themes and subthemes; therefore, they are not meant to be indicative of a comprehensive

illustration.

Presentation of Themes

Five overarching themes were identified after several iterations of the data as detailed in

Chapter 3. These will be discussed in greater detail below—including sub-themes when

relevant—along with supporting quotes and negative cases (Riessman, 2008). Themes are considered when patterns and trends have been identified in the data (Braun & Clarke, 2006; Patton, 1999). As noted earlier, there is not a standard for the number of participants to contribute to a theme (Braun & Clarke, 2006); therefore, I followed the research of Tasker and Stonebridge (2016) and a theme was considered so long as it had at least four of the seven participants contribute to the overarching theme, not the sub-themes that organized into the overarching theme. Research questions one and three were addressed in the first four themes that were inductive, or data driven (Braun & Clarke, 2006). However, the second research question, which explored what participants' narratives revealed about how their identities were shaped, employed a theoretical thematic analysis (Braun & Clarke, 2006) based on the earlier work of Lilgendahl and McAdams (2011) and McLeane and Thorne (2003) within the context of self-growth. Negative cases, or alternative explanations, are instances that do not fit the pattern or are exceptions to the theme, which may expand, alter, or appear contradictory (Mays & Pope, 2000; Patton, 1999). To strengthen persuasiveness, Riessman (2008) argues their use in the presentation of data. Table 3 provides a listing of the five overarching themes, along with a brief description.

Theme One: Separation and Alternative Caregiving

Following a physical burn trauma, it is likely injured siblings will experience a lengthy hospitalization, as well as ongoing medical treatments, that result in uninjured siblings being separated from their injured siblings—and usually their parents—fostering feelings of isolation from the family and a disrupted existence. Consequently, uninjured siblings are frequently supervised by someone other than their parents and often not in their own residence, which can

heighten their sense of disconnection from the family and home. Six out of the seven participants verbalized enduring separation and alternative caregiving.

Amber recalled her brother being hospitalized for "almost six months" in a specialized burn center that was over 1500 miles away in another country, which required transportation by land and sea. She described:

We didn't see him until he got back from [the hospital]…we just seen [*sic*] pictures that my aunt sent us…or what we heard on the news or talked to him on the phone; but we did not see him for the time he was away and getting fixed.

Amber longed for connection with her brother. Yet, she described challenges to even talking to him on the phone, "[H]e couldn't really hear us because he was in ICU so he had a bubble over him, plastic, so he couldn't really have too many people. He couldn't even hear the phones because of the plastic. It was hard." Even when he was discharged from the hospital, Amber recalled, "He could be home for a few months, go again for another month or so, a week, come back again. That was adjustment that we, as siblings, had to get through." In addition to her brother's absence from the home, Amber's dad sustained burn injuries to 35% of his body "just trying to get [Cody] out of the fire," which resulted in his roughly two-month hospitalization.

In Amber's situation, she reported her dad was the primary parent stating, "[M]y mom walked out on me when I was 10. Yeah, we were raised by my dad." Therefore, since he was hospitalized himself, one of Amber's paternal aunts went and stayed with Cody at the burn center. Meanwhile, two other paternal aunts and her paternal grandmother became the alternative caregivers for her, as well as her three other siblings. She reported, "They all took turns helping and watching us while [my dad and brother] were in the hospital, so we could somewhat continue our normal life after what happened." Amber's family home was lost in the electrical

fire that caused the injuries to her dad and brother. Despite the family's acquisition of temporary housing she maintained, "[W]e were going to my house, to my grandmother's, to my aunt's because my grandmother was old, she couldn't deal with four other kids." As a result, the sense of disconnection and uncertainty sustained in the face of losing their family home, the lack knowledge for where they would be physically from day to day—even in terms of sleeping from night to night—or who was providing supervision. She concluded, "It was always on a roller coaster up and down what was going to happen. It was never a solid family, there's always something going."

Although it was not as geographically challenging for Emma's sister to receive medical care for her injury, Emma still reported:

[W]hen [Isabella] was initially burned, my parents were gone… I think it was six weeks. They were gone the whole six weeks. I may have saw [*sic*] them once or twice. I don't remember seeing them at all. I just was with my grandparents. Then when she had her surgeries, I think that on the day of the surgeries, I would stay with grandparents. Then after that, one parent would always come home to stay the night with me, at least when things were well.

However, in the chaos that ensues the acute burn injury incident, circumstances may dictate an absence of time to urgently locate family. Although Emma eventually ended up at her grandparents, she is unsure of the exact timeline, adding she believed, "[A]t the very least, it was probably five days later, but at the most, a couple of weeks." Until then, following Isabella's acute injury, Emma recounted:

    [B]eing at the neighbor's house. A neighbor that my parents didn't really know very well, by the way. Just a neighbor across the street. The girl was a few years older than me. I remember playing in their living room by their coffee table.

Therefore, based on individual contexts, at times the people caring for the uninjured sibling may be people their parents—and the child—do not know very well, which compounds the strain and uncertainty of an already unsettled situation.

    Ursala remembered being separated from her parents, as well as both her sisters, after they were injured in a campfire incident. Ruth was hospitalized for almost six months and Rose about a month. Reflecting back on Ruth's longer hospitalization Ursala reported, "It was a long time. It seemed like a long time that we were apart, and when we finally got to get together, it was exciting to be able to see her." It was a couple of months before Ursala was finally allowed to visit Ruth in the hospital. She shared, "[I]t was just weird with her gone and me not really being able to pick up the phone like we could today to talk to her." Ursala also narrated alternative caregiving following her sisters' injuries by a neighbor:

    [M]y parents slept at the hospital that first couple weeks, and so I stayed with a friend at their house who just happened to live about five or six doors down….I stayed with the neighbors for probably two weeks and kept saying, "When can I come home? When can I come home?" Then my dad eventually had to go back to work, and my mom didn't work at the time. She would stay at the hospital, and my dad would come relieve her. I did get to go home after a couple weeks….It was hard 'cause I kept wanting to go home, and the family was very, very religious. I didn't know how religious until I lived with them for a couple weeks. The mom was kind of strange. She would walk around the house telling

Satan to get out of the room and things like that. I'm like, "Oh, my god. I gotta get out of here."

Similar to Amber, Alyssa's family also experienced a house fire following the gas can that ignited, burning sister Tiffany, and subsequently their entire family home consuming "everything but the bricks." She detailed her experience:

After that situation your whole world flips around. Me and Tiffany were, you couldn't separate us. And then, next thing you know, the next few months you are separated and you don't really know where you're sleeping that night because your house is burned down….That's what makes it the worst and watching your sibling, your whole world just, especially when your sibling is your world, they're your best friend, the person that you've always had, just kind of disappear for a few months.

Alyssa found herself estranged from her entire nuclear family and their home after the incident. Her dad—injured while saving Tiffany—was briefly hospitalized for his burns and smoke inhalation, which left her mom to stay at the hospital alone until he was released and could join her. Depending on the family's availability she would stay with either her maternal grandmother or aunt; however, Alyssa also detailed being cared for by others, "Sometimes you're with people you don't know, they're not the nicest people, they're nothing like your parents." She explained:

[T]he next thing I know I'm in this stranger's house and she's hurting me type deal. I only stayed with her a couple of weeks till my parents started noticing different types of incidents that was [*sic*] happening. I got taken out of her [house] and went back to just staying with family. Then, I stayed up with my parents at the hospital a lot.

Alyssa chronicled the woman, a friend of her grandmothers, was subsequently arrested after her parents found out what happened. During this time, 3-year-old Alyssa was additionally separated

from her old brother Tyler, also spared from any burn injuries. She advised her brother stayed with a friend "that lived up the road, but they couldn't watch me because she had three boys and they didn't think a girl in a house full of boys [was a good idea], especially beginning to be teenage boys also." The overall instability—expressed as "bouncing around''—on top of the abuse Alyssa suffered at the hands of one of her alternative caregivers, was deemed an emotionally disruptive experience, "[Y]ou're stressed out, hurting all the time."

Oliver also articulated separation and alternative caregiving as noted above by other participants; though he did not suggest it was an added emotional stressor. Oliver assumed he was already at his grandparents' house who lived nearby when Scott sustained his burn injuries since he brother was sick at the time. He described Scott's treatments, "It was back and forth, back and forth. He was in and out, in and out constantly for skin releases and skin grafts and all that stuff." Therefore, Oliver articulated periods of intermittent estrangement from his brother and parents. However, he noted growing family instability over the years; thus, his experience with his grandparents—his primary caregivers in his parents' absence—appeared to have been a source of respite in his life. He recalled fondly:

> It was always just play and have fun and pretend everything's fine with my grandparents. It was a good place to be, because it was a safe place. Nobody was fighting or anything. They were just always fun with us…and loving with us kids.

> Isaac's brother was initially treated at a local hospital and discharged home; however, the next day his parents took him to see a doctor and they urgently recommended Noah be taken to a burn center, where he was admitted. Isaac was unclear the duration of his brother's hospitalization but recalled staying with his aunt for several days while his parents remained at the hospital with his brother. He explained this separation from Noah was distinct, "I think that

was the first time in my memories where Noah was considered my brother," adding he denied

his existence up until that age as "just a kid that was around me when I was a baby." Noah's

injuries required ongoing care at a specialized children's burn center miles away from home in

another state. If Isaac was in school, he would stay back with either his aunt or one of his

parents. For the bigger surgeries, which they tried to schedule around school breaks, he would go

with his parents. However, even if he went with his parents he recalled staying with a family

friend in the area, "We had a friend that lived in [the area] that we would go stay with and I'd be

at that house for a while, while my brother was getting the surgeries done."

     Conclusion. Michael was the only negative case located for this particular theme.

However, his situation was unique from the others since he was born after his sister sustained her

injuries; therefore, he did not articulate memories of separation or being cared for by others in

the years after he was born. He also denied the necessity for ongoing medical treatments when

she was older, which negated the opportunity for him to experience separation and/or alternative

caregiving. Aside from Michael, all other participants verbalized separation from their injured

siblings, as well as their parents, for both the initial burn injury and/or follow up

surgeries/treatments. Furthermore, they expressed being cared for by others—or alternative

caregiving—during these often prolonged acute and intermittent treatments.

     Though Isaac verbalized being separated from his brother and parents, while being cared

for occasionally by his aunt, the memories of his experience do not appear to generate emotional

responses as formidable to the conditions as others. Isaac was young when his brother was

injured; yet, he was about the same age as Alyssa and Oliver. However, in addition to Alyssa's

sister's injury, she simultaneously grieved the loss of her family home and most of their

possessions, as well as physical abuse suffered in the hands of an alternative caregiver.

Additionally, Oliver noted he began to experience increased discord in the family in the years following his brother's burn injuries, positioning time with his grandparents as a reprieve. Therefore, the intensified response to being separated from their family, as well as being cared for by others, may have been precipitated by the inherent difference in their circumstances as noted above. Or more simply, Isaac's involvement of separation and alternative caregiving was not his most emotionally prominent recollection. The next theme will examine altered interactions and ambivalent roles.

Theme Two: Altered Interactions and Ambivalent Roles

Burn injuries are a physical trauma to the body that can cause temporary or prolonged cosmetic changes, as well as renegotiated mobility and/or activity levels. The injured sibling may have wounds that are still healing, which require dressing changes, as well as the use of pressure garments in recovery and scar management. Furthermore, they are likely to participate in both physical therapy to assist with range of motion and/or functioning of their body and occupational therapy to improve their ability to perform activities of daily living (e.g. bathing, dressing, eating). Aside from exertion due to the activities noted above, injured siblings are also more likely to have increased and prolonged post burn injury fatigue (Shi et al., 2018; Simko et al., 2017). Therefore, the physical transformations to their body generates nuanced adaptations to how others engage (or disengage) with both the injured individual and their family. Changes in family functioning are also likely. Consequently, all uninjured siblings experienced new interactions and roles (e.g. caregiver and/or protector/advocate) in the family and with others.

Questions and stares. Uninjured siblings experienced heightened awareness to how others responded both directly and indirectly to their injured siblings. Amber recalled when she returned to school after her family's house fire:

It was [a] shock because everyone asked questions and I didn't know what to say, so I would always avoid it, so I didn't have to deal with it because I didn't want to. But a lot of questions and [they] ask[ed] why did it happen, how did it happen, stuff like that. It was hard for a bit.

Ursala fielded questions about her sisters as well, especially since Ruth was hospitalized for so long and not able to return to traditional schooling for a year. Whether people asked her directly or not Ursala sensed their curiosity. She shared, "[T]he whole school knew what had happened. I just felt like everyone was lookin' at me like, 'Tell us what happened' and 'How is she doing?'" Emma also received lots of questions from her peers. She reported:

There were a lot of questions—like, "What's wrong with her? What's on her legs? What happened?"—which I was always open to answering, especially when I was older. When I was younger, it was annoying—or it wasn't so much annoying as it was it almost felt rude to ask. Then when I got older, it was more like I understood…They just wanna know. They're just curious. She is different.

Emma admits she used to get tired of people asking her questions all the time but said "It doesn't happen so much anymore." When people did ask, she would comment:

My response—I would tell them what happened. "When she was little, she was burned." "How'd that happen?" "Oh, she walked into some ashes." That's the end of the conversation. You don't really need to give them any more information.

Isaac endured a similar line of questioning around what happened accepting that his brother's scar was noticeable. He described:

I never really heard anything negative about it, but I was often questioned about what happened. Say we met a new group of kids that we'd be friends with in the neighborhood

or just when we were at church and stuff, they would ask me about it because they didn't want to ask him personally because something had happened to him. They knew I was his brother, so they'd ask me what happened because it was very, very visible when he was a child before he had all the skin graft surgeries. It was a big clump of scar tissue that was bright red. It popped out. Everybody saw it. That was the first thing they saw when they looked at him.

Isaac denied giving the line of questions much thought; instead he commented, "I knew why they weren't asking him just because that was, I guess, it'd be kind of rude to ask about, 'What happened to you?' Even as kids, they knew not to ask him about it. They'd ask me." Still, he had different feelings around the perceived looks his brother got and offered this suggestion:

I'd say just don't stare. That's one of the biggest things. It kind of bothered me. It didn't really bother my brother, but it kind of bothered me watching other people turn their head and look when it was very physically noticeable….I just felt like they were being rude by staring at him….so I wish people wouldn't stare.

Oliver detailed his experience with his brother's cosmetic changes in childhood and denied them being prevalent to him when they engaged with each other. He reported:

Because we were so young, I really didn't see his scars so I grew up not really seeing them too much until he would go for a surgery or something. I notice when other people looked at him more, but myself I didn't really—he was just my brother, so I didn't see the scars.

However, when it came to other people, they interacted with he stated, "[I]t was always just as a child just wanting people to stop staring at him and wanting people to just—I wanted for him not to be burned."

Differential treatment. In addition to altered ways the public interacted with injured siblings, uninjured siblings recognized changed family dynamics, specifically when it came to relations with their parents. Emma perceived her sister Isabella's burn injury as an incident that exacerbated the family's already strained dynamics. She articulated:

> I know some parents say that they try to give equal attention to their kids, but there was no equal attention here. It's something I've forgiven them for, and it's something that I've moved on from and we've moved on from as a family, but for several years I hated all of them.

Particularly, she chronicled her mom's mental illness diagnoses and the challenges they experienced in their relationship, where she often felt like she had to assume the maternal role. Although she acknowledged, "She definitely stepped up when the accident happened, in terms of taking care of physical therapy and all of that." When it came to her dad, Emma reported, "He's basically been [running] a single-parent household with three children." She explained:

> [M]y dad being the only adult around, and all of his attention goes toward my mom and my sister, because I was there and could take care of myself. By the time I was five, I could make my own food and do everything that a ten-year-old could.

Consequently, Emma affirmed the hatred she felt was not isolated to Isabella's burn injury, but rather the ripple effect it had on then further maxing out her mom's depleted capacity to parent, which then resulted in her dad juggling his struggling wife and injured daughter.

Isaac struggled with both the attention, as well as the physical possessions he observed as differential treatment his brother received. He detailed:

[H]e was always the first person to get anything because, one, he was the oldest, and two, he needed something to occupy his time because he didn't have the opportunity to go out and do a lot of other things that were outside, particularly.

Isaac recalled a distinct memory of his brother receiving a coveted video game, "I was really upset about that as a kid because my grandma bought it for him because he had to do all these long drives up to [the specialty hospital]." He also added that as a result of Noah's medical conditions, "We couldn't really go do a lot of stuff." Isaac suggested greater awareness of the other child(ren) when something traumatic happens, noting, "He did get a lot of attention, a lot more attention, and even it wasn't positive attention—because it was always "I'm having to attend to his needs'—but it was still attention."

Oliver posited his parents lack of attention could have been due to them being "very much wrapped in their own stuff all the time," perhaps even because of the guilt they felt around Scott's injury. However, he articulated his brother has "gotten away with a lot more because of his scars." When asked for a specific example he stated:

I can tell you right now with my brother and sister's substance abuse, my sister was very much made to feel like there was something really wrong with her, whereas my parents pretty much…they never really addressed it or did very much...I think that they kind of just let him be like, "Oh, he has enough to deal with. We'll just let him do what he has to do."

However, for Oliver the different attention levels were welcomed. He clarified:

I never really wanted attention. I was better if they just left me alone. I was almost grateful that they were giving all the attention to my brother if that sounds weird or whatever, but it was like "Oh God, thanks. Just leave me be and give it to him."

When Cody returned home after his six-month hospitalization, Amber and her siblings—especially her middle brother—grappled with their similar feelings about the treatment of her brother. She detailed, "[T]hey were all pretty much jealous because Cody was the focus of attention for a while because of everything that happened….There's times I still feel that way…Not going to lie. It is what it is." Though for Amber, she clarified it was primarily within the context of all the help he received for school and other things, while she verbalized being put in the position of raising her four siblings when her mom left the family and therefore went out on her own at a young age. She explained, "I left my help, parents, when I was 18 so no one was ever there for me. He was lucky to have people there helping him out for school, for everything."

Caregiver. Aside from managing altered interactions with the public and the changed dynamics within their family, uninjured siblings frequently found themselves in a position of assuming new, and sometimes ambivalent, roles with their sibling, such as caregiver. Alyssa detailed:

> After getting the initial shock of it, it was a lot of adjusting. It was like bringing a newborn home. Tiffany's basically growing new skin back, it hurts. Every time you moved her, she screamed. I had my best friend back, but I couldn't do anything with her. I was three years old wrapping a bandage. When you have to change bandages, put more Silvadene on, those screams would haunt you in your sleep….[Y]ou go through the motions, you wake up, help her in the mornings, any time she hollers, you run. Pain medicines, you learn exactly the time of when pain medicines should be taken. You become more of a caretaker than a sibling at that point.

Alyssa recognized as a young child she may not have initially participated in all aspects of her care; however, she reported:

> I would sit there wrapping and my parents never let me take it [the bandages] off because they said they didn't want that image in my head, but I'd sit there and watch them do it. I learned how to do a tight gauze wrap, I learned how to do a splint…but I was always there. I was the one holding Tiffany's hand while basically ripping clean flesh off.

As difficult and conflicting as that was, Alyssa declared, "Sitting there talking to her was worth it." Her role as caregiver to her sister is one she perceived as ongoing. She stated, "She's 20 years old and still having surgeries. You sit there and all I want to do is make her life easier. She's down for surgery right now and I do everything for her." Alyssa went on to explain, "I'm keeping a second job to make sure our bills don't fall behind. I searched high and low trying to find that knee scooter. I'd do anything for her."

Aside from already assuming a parenting role in the home following her mom's absence, Amber expressed new roles in caring for Cody. She recalled, "I used to go to most of his therapists' appointments when I could. Especially if it was summer time, it would be me." Again, she felt conflicted adapting to him being at home:

> I think it was a bit of mixture of good that it was back to normal but we also had to deal with the changes that we had to go with seeing Cody's bandages changed every day, going to therapy with him, making sure [he has] his fresh bandages, going to therapy, making sure he's walking, keeping him active so he didn't seize up and stuff.

Taking care of him was not always specifically about his medical care, but instead how she commonly physically engaged with Cody, similar to what Alyssa voiced above about being mindful of the healing skin. She explained, "[Y]ou have to be careful in what you were doing with him. If you were lifting or playing with him." However, she admitted, "I didn't care, I always treated him like my other brothers, even when he was burned."

Emma was not solely responsible for Isabella's day to day dressing changes and physical therapy—something she denied differentiating into two separate categories—that was her mom's job. She stated, "I don't believe I had to ever assist with physical therapy or anything like that." Yet she also acknowledged:

> I know there were a couple of times where I'd help hold her down…I don't remember if this was initially or after her second surgeries and everything… I'm sure that at some point when I was that age, I had to help hold her down at least once or twice, but for the most part I don't think I was really involved with that.

Though she was unclear the specificity around assisting in her sister's care, any experience Emma perceived—even "a couple of times"—was deemed relevant to her experience with caregiving, due to the graphic auditory memories she recalled just listening to her mom perform Isabella's physical therapy alone. She described:

> Again, with the screaming. That's basically the main thing I remember…She had purple pressure garments….They were on her hand and her legs. Then I remember my mom would take them off to do the stretches. At least I think she took 'em off to do the stretches. I would go in my room and turn the TV up as loud as I could and try to zone her out as much as I could, but all I can remember is the screams. I don't remember what I was watching. I just remember the screams.

Emma vividly articulated her sister's screams at both the acute incident and in Isabella's ongoing medical treatment. She disclosed it has been a trigger for her at times, commenting these incidents "brought back all those memories, and I didn't even know it was something I remembered," which again supported the rationale for inclusion of this data regarding caregiver.

Protector. Another often added role for uninjured siblings was that of protector. At times, the impetus was to manage the cruelty of others. For example, Ursala remembered her family going to swim at a pool they belonged to after her younger sister's injuries healed. If anyone said anything about Ruth's physical appearance, she jumped in to defend her sister; though not physically. She narrated, "I would just—not physically attack, but try to get 'em away and say, 'Don't say that. That's not nice'….I was just very protective, and if anyone said anything, I would get after them."

Other uninjured siblings reported more physically assertive means. Michael described instances of neighborhood kids being unkind to his sister Irene when they were young. He stated:

> [A]ll the time we had a couple kids that we'd be out just doing kid stuff, playing and they wouldn't let her play or they would say something about her hands looked funny and ended up in little brother getting in fights and trying to stand up for her 'cause she wasn't gonna say anything back to 'em…. There's a few specific stories where kids wouldn't let her ride bikes with us or jump on the bed or you know, little kid things because her hands looked funny or her hands looked different.

Michael acknowledged many times these encounters did not seem to bother his sister; however, he added, "[I]t bothered me because it was my sister."

Alyssa also admitted employing physical tactics when people said something, she deemed inappropriate and hurtful, which she chronicled as most of their school years:

> [T]he next thing you know you're taking care of them, your protector, you're beating up kids at school that want to say something about her. It changes you. I was supposed to be, who knows, I was supposed to be the nice girl, pretty in dresses, but I grew up tough, grew a tough skin, fought a bunch of kids in school, stayed in trouble, but in my head it

wasn't trouble, it was protecting….Someone said anything offensive towards Tiffany's burns, I was that kid that swung. Of course, my parents always taught me, never throw the first punch, but I felt their words were the first punch. Got in trouble a lot, stayed in trouble.

About the time she finished high school, Alyssa had an opportunity to attend a weekend burn camp that included uninjured siblings. It was then she professed learning the value of trading in her fists for words as a means to defend her sister. She detailed:

Educate them. They don't understand. They don't have the understanding you do. They don't know what you've been through to see them like that. My attitude kinda shifted on everything. I've had a couple more incidents of when someone would insult her and I found by [*sic*] educating them was such a better hit, because they would sit there and they were like, "Wow, I feel like an idiot." It was a lot more satisfying, a lot easier to heal. A hand break hurts.

Besides physically or verbally protecting Tiffany, Alyssa also detailed dismissing people and refraining from activities in an effort to support and shield her. She recalled, "I had friends, but my friends didn't want to come near Tiffany, so I dropped my friends." She also related:

I didn't do sports because Tiffany couldn't. Anything that Tiffany physically couldn't do, I avoided because I didn't want her to feel bad about it…Played softball for a little bit, I was really good at it, but then watching Tiffany on the sidelines wanting to do it makes you lose interest because you're like, it's not fair.

At other times, uninjured siblings withheld their feelings or refrained from honest dialogue as a means to spare their brother or sister at their own expense. For example, Amber expressed how much guilt she felt about her brother's injury, which she still carries. She believes

he knows how she feels; yet, denied the two of them ever having a true dialogue about it, stating she "got too worked up" and noted the following concerns:

> I don't want to beat him down or anything and if I have it [the conversation], I just would probably have it with somebody else just to get it off my chest because he's doing so good, but I don't want to see him feel bad for me.

Alyssa also withholds her emotions, in addition to hurtful experiences, from Tiffany as a protective tool. During Tiffany's hospitalization, while she was in the care of her grandmother's friend, she recalled the cruelty of her caregiver, "She would stick me in a corner, she used to beat me, she beat me when I spilled milk one time and that's something that we just kind of hide from Tiffany." Alyssa furthered, "[I]t's kind of like an unspoken subject in the house, mainly because we keep it from Tiffany. She blames herself for the fire and we know it. I don't want her to blame herself for something that's history." Although Alyssa articulated how close she and Tiffany are, an emotional inequity appears prevalent that she recognized:

> For us to have that bond, to be able to talk it out, and I guess a lot of it, of not talking to Tiffany about it, is my fault. I've had plenty of opportunities to share with Tiffany, but I chose not to bring it up….Because I feel like it would hurt her all over again. I would bring it all back up, stuff that we moved on from or say we moved on from or just bottled up… but I'd rather cause me more damage than cause all of us more damage. It's just controlling it.

She further elucidated the perceived roles within the context of their relationship:

> We all pick our people we like to open up to and it's—I would like to say Tiffany's my person I would open up to, but she's not. She's the person I take care of. It's hard to switch

roles because I want to see—I've always been seen as the strong person to her. I feel like if I open up to her, I'm not that person anymore.

Oliver chronicled feeling like he had to protect his brother from himself and his parent's inattentiveness. He recalled:

There was a lot of our childhood where I felt like my parents weren't watching my brother and sister at all, so I felt like they were endangered many times. My mom would let my brother go walk along the edge of cliffs and go do things. My brother was a very adventurous child….There was always that thing of, "Oh God, I've got to protect these kids all the time."

Oliver later questioned his mom about what he observed as her overcompensating with Scott by allowing him to engage in potentially dangerous activities and reports she replied, "I was building his confidence. I knew he was going to have a hard time."

Several uninjured siblings also expressed recognizing that their injured siblings were having a hard time with others, most frequently when it came to peers at school, and at times realized they did not do much to assist. Emma recalled she knew Isabella was bullied a lot in high school but said she never really knew who did it. She remembered Isabella coming to her and explained:

She'd bug me a little bit, but I never really thought much of it, and I really didn't do anything to help. If she was lonely, I'd stay with her and comfort her and everything, but I never really did anything to help her with the bullying or any of that.

Some also felt their own insecurities prevented them from intervening and protecting their siblings more. For example, Oliver detailed:

I was pretty insecure and shy, and he was pretty much teased and bullied and all that kind of stuff, yeah. Because I was insecure and shy, I couldn't really do much to help him or stick up for him or stuff like that, yeah. It was awkward. School was very awkward. It wasn't a good experience.

Emotional embargo. Though not overtly expressed by all participants, the sub-theme of emotional embargo was chosen for inclusion based on its substance and implications. Alyssa articulated several examples of ways she felt like her experience—as someone without a physical burn injury—was directly minimized when she engaged with others following the incident. Alyssa verbalized it as "just being kinda kicked to the side." She recalled the adjustments after Tiffany returned home and her own anger; yet, when she described expressing her anger, or what she termed "show[ing] out," others would tell her "Hey, you could have it worse." When this was said, Alyssa stated, "Then, you just kind of build your own little bubble and you stay in it." Furthermore, she ceased having feelings about things and felt a void of someone who she could talk with. She perceived that due to her parents focus on her injured sibling, the option of therapy or other resources would be ruled out as "not really that important." Instead, she felt that she was supposed to talk to her parents, but explained, "It's hard talking to a parent when they're like, 'Hey, but you're the sibling that wasn't burned.'" She acknowledged:

Even though parents, they try to be sentimental to it and everything…It's hard to sympathize feelings, because in their eyes they're like, "Hey, you got out lucky too. I got out lucky. I wish it was me," type deal. That's how their coping mechanism works. But then, there you are stuck on your island. Every time somebody says, "Hey, at least you weren't burned," sticks you back on your island and you just kind of stop talking about it.

Alyssa recalled a specific example from one summer when they dropped her sister off at burn camp—Tiffany's respite from the world and place to make connections—and how Alyssa challenged why she was not allowed to participate in the program, to which her sister replied, "Well, you had to be hospitalized for a burn." Several of Tiffany's friends and volunteers even commented, "Alyssa, we wish you could stay." She felt confused and alone, "[A]ll I did was question why, 'Why can't I? My house burned down too. I've lost just as much. Only thing, I got out.'" She even remembered telling one of the volunteers, "I wish I was burned so I could come," and added:

> I'll think about it and I'm like, that's probably not a good thing to say. Tiffany shifted into another community, but it left me kind of on an island, because I'm like, "I'm the sister, what am I supposed to do? I've been through it all too, I've seen it all."

She recalled how alone she felt, "[S]he'd come back and she's like, 'Yeah, this person went through this, this person went through—' she'd tell me all their stories and I'd just think, 'Who am I supposed to talk to? Who understands my situation?' For over 14 years Tiffany participated in the burn camp and developed her sense of community with campers who shared a similar experience. However, Alyssa professed, "She's [finding] understanding and I'm back on my island." Though Alyssa's island was a figurative example of her experience, it provides a powerful illustration of her isolating experience when reminded by others, "At least you're not burned."

Conclusion. From this data a negative case was not located. However, a negative case could be an uninjured sibling who did not experience any altered interactions or ambivalent roles with their injured sibling or the public. Again, Michael was born after his sister's injury, but still articulated serving as a protector to his sister. Furthermore, all other uninjured siblings in this

study articulated some kind of changed relations and uncertain roles (e.g. caregiver and/or protector/advocate) within the context of their family and sibling relationship, as well as with others. Additionally, Alyssa verbalized explicit instances when engaging with other—likely well-intentioned—when they diminished her experience as the uninjured sibling, it what was deemed as an emotional embargo. The next theme will examine (r)evolving emotional pain.

Theme Three: (R)evolving Emotional Pain

Uninjured siblings frequently endure a multitude of emotions following the injury of their sibling. The myriad of reactions originates at the acute incident and continues to evolve, and revolve, often sustained through hospitalization, aftercare, and community/family reintegration. However, through the passage of time and maturation, the emotions frequently advance through adversity into acceptance and understanding. Challenging feelings verbalized by six of the seven uninjured siblings include anger/frustration, confusion, depression, envy/jealousy, grief/loss, and guilt.

Anger/Frustration. Frequently, participants expressed anger and/or frustration that stemmed from some of the perceived inequity in treatment discussed above, as well as general adjustments after the burn incident. Amber provided the example of her two younger brothers' response to the added attention her injured brother received, "They took it out with the anger and they always, 'Oh, Cody this, Cody that, Cody gets this attention, Cody gets that attention,'" and also admitted she still feels that way at times. Additionally, Alyssa noted her anger, also discussed earlier, around the hardship of Tiffany's return home from the hospital. She stated, "It was really hard adjusting. I was angry." This was further compounded when others dismissed or diminished her feelings. Isaac acknowledged frustration about the resources he felt his brother discarded subsequent to the financial settlement he received from his burn injury. Though his

brother did attend college for a period of time, Isaac adds he did not finish, but, instead, "He threw it away." He detailed:

> He's never really sought to do more with himself and I've just kind of seen him give up on a lot of things over the years, which is kind of tough for me because he's my brother. I don't think a kid at that age should have that kind of money to do what he wanted to do.

Confusion. For many uninjured siblings, confusion stemmed from not understanding implications of the incident, their siblings care, or dynamics within their family. Alyssa recalled:

> Being so young you don't really understand. You know fire destroys things but you don't know to what extent. You know when you touch the stove, it hurts, so how much pain is Tiffany actually in if she was just stuck in there? You have a lot of questions, but not sure how to ask because you're the kid.

When Ursala considered the first visit with her sister Ruth at the hospital, with a curtain between the two of them so she was not able to see her sister's changed appearance, she reported:

> It was scary 'cause I didn't understand why I couldn't see her. I thought, "If I'm gonna eventually see her, what's gonna change between now and a month from now?" I didn't understand why I couldn't see her if I could talk to her through the curtain. I knew it was probably gonna be something shocking and that was probably [why], they didn't want her to see my reaction and just to be prepared for seeing her for the first time.

Isaac reflected on his behavior when he started preschool, noting that it was around the same time his brother was injured and recognized that was also when "[h]e started to become more introverted and started really pushing [him]self away from people." He remembered

frequently getting in trouble for pulling other kids ears and recalled that he was the one who "had to sleep right next to the teacher because I wasn't allowed to be unsupervised." He stated:

I look back at it [and] I'm like, "Why the hell did I do that?" You don't know why but I see that around that time period I was, I guess you could say, confused. I didn't really know what was going on. I'd just get sent to school and that'd be that.

Lastly, Oliver detailed his bewilderment when learning that not every family shared the same experiences that his did. He stated:

[I]t's a weird situation when you have a sibling and you're that young that has that happen to you because you don't realize that everybody's not going through that stuff. You think it's kind of normal, you see what I mean? It's like there's a lot of confusion when you're really young like that. You don't know if that happens in every family, you know what I mean?

Depression. Three of the participants explicitly acknowledged enduring depression at some point following the incident. Though highlighting their experience is not meant to suggest causality, it is still an important finding with practical implications worth considering. Isaac reported recognizing his depression after high school and stated, "I slowly worked my way into depression for about four years of just being alone;" however, he denied receiving any formal treatment. He added, "I didn't have anybody. I had my brother, but…we barely spoke. I'd be playing video games, the only people I talked to was on there and that's it. I didn't really interact with family too much." Alyssa also confided her challenges with anxiety and depression, but indicated, "It's something I deal with on my own," and did not elaborate beyond that statement.

However, Emma expressed attending therapy after her parents observed changes in her behavior and became concerned about her depression, especially since her mother suffered from

diagnosed bipolar disorder. It was during therapy Emma reported her family learned, "I hated them. I hated all of them. I think they started to realize how much that they had neglected—it wasn't so much neglect as it was just that they didn't have time for me." Emma confided she also struggled with self-harming behaviors, as well as a couple of suicide attempts. Her last hospitalization was around the time she was 15 or 16 years old, which she explained:

> I think the reason it was the last is because I really started to open up about things that had been going on and was able to move past them. By that, I mean I told my mom that I resented her. I told my sister that I resented her and finally opened up about how I was actually feeling. It allowed me to actually utilize the coping skills they taught you and move forward. It has not been an easy road, moving through all of this. I know part of it is because I am also bipolar, but I can't blame all of that on being bipolar….I can't blame [all the issues] on being bipolar cause it's not just a chemical imbalance. I've not had an easy childhood.

Envy/Jealousy. Though they are discussed in the same sub-theme, envy and jealously are distinguishable emotions. While conceptually discernible, they often share overlapping meanings due to linguistic ambiguity; therefore, jealousy is often employed for either jealousy or envy, whereas envy is used more definitively (Smith, Kim, & Parrott, 1988). Generally speaking, envy is conceptualized as wanting something someone else has, such as a quality, achievement or possession, or wanting the other person to lack it (Parrott & Smith, 1993). Whereas, jealousy is fearing something you have—generally thought of in the context of relationships—will be taken away (Parrott & Smith, 1993).

Alyssa exhibited both emotions around the concept of summer camp. She longed to attend the program like her sister did and experience a sense of community in the hopes she

would find "that one person to have a common ground of understanding"; and, she felt jealous of

its impact on their relationship, noting, "I hate burn camp because I don't know what to do when

[Tiffany's] not here." Isaac also expressed envy around his brother's attendance at burn camp

after Noah returned the first year and told his brother everything they did. He remarked, "He had

a really good time, which I'm really glad he did go, but I was a little jealous of him going to

camp because I was like, 'I want to go do stuff like that.'"

Similar to the emotions of anger/frustration, envy/jealousy are also entangled in the

experience of differential treatment discussed earlier. Emma articulated:

> I resented her for a very, very long time… She got all the attention. She went through
>
> phases where—like for a while she hated my mom, and she wanted to hurt herself….She
>
> scared us all. It was like she demanded all the attention all the time.

Isaac reported shared sentiments regarding the physical possessions and attention his brother

received, stating, "At the time, it was very 'this is unfair.' I'll be honest, there was [*sic*] times

where I kind of wished I'd gotten burned so I could have all of that."

Grief/Loss. All of the uninjured siblings endured grief/loss in terms of the physical

presence of their parents and injured sibling, as well as a sense of normalcy or routine in their

family. However, Alyssa and Amber experienced grief /loss unique from the other participants in

this study. In addition to their sibling and parent injuries', they also lost their home and personal

belongings. So, aside from the alarming shock of being separated from her parents and sister,

Alyssa commented, "[Y]ou don't really know where you're sleeping that night because your

house is burned down." She added:

> You don't know what to do. You want to go to your house and get your stuff, but your
>
> stuff is gone. You're told that everything is gone….We couldn't have any of our stuff

back because something about toxins and it has to be sent off to get cleaned and, trust me,

when they go do that, it's not going to be the same. Most of the stuff was ruined. We had

to go buy other stuff.

Similarly, Amber articulated her experience losing her family home—the house her great-great-grandmother gave her dad—that she had grown up in:

All I remember was when I got to see the house it was half falling down, there was some

siding left, all smoky, you can tell it was pretty much totaled, that it was bulldozed down.

There was no saving it…It was hard. Well, I was young, so it's—now that I'm older, it

was difficult, but I lost everything after, so not having no memories, no pictures…stuff

like that, was hard.

Guilt. Many of the injured siblings are haunted by the powerful emotion of guilt, as they try to navigate the waters as the one without a physical injury and/or contemplate what they could have done differently to prevent their sibling's injury. Alyssa recalled a conversation she had with another uninjured sibling at a weekend program over a decade after her sister's injury around her feelings of guilt. She recanted:

There was another little girl named [Abby], she told me her story and I'm like, "Look, it's

okay to feel that way. It's perfectly fine to feel guilty, because you're a survivor.

Survivor's guilt. Of course, your sibling lived, but still you see them hurt, but it's okay for

you to hurt too. It's perfectly fine to have feelings."

She remembered, "[Abby] blamed herself and I saw how I blamed myself, how I wish I could

trade places even just for a minute to feel [Tiffany's] pain, to take the pain." It was a powerful

moment for Alyssa, as she recalled the young girl said to her, "This is what I've been waiting

for…is someone just to tell me that it's okay… I don't have anybody to talk to about this. We don't have other burned kids around."

Oliver's struggles with guilt were over his own appearance compared to his brothers. He admitted, "[T]here is a certain guilt that happens to the kids that aren't [burned/scarred], in the family." As a child he recognized "that society sees them as different or flawed or something." He confessed that as a kid:

> [Y]ou feel a little bit guilty, because there's nothing wrong with you physically as far as you're not scarred. When somebody tells you you're attractive or something, you go, "Oh no, don't be telling me that…." I can remember cringing at that stuff when I was a little kid.

Amber disclosed her continued struggle with one question, "Why, why, why?" While staying at her grandmother mother's she had a conversation with a priest, explaining, "I was blaming myself saying, 'It's my fault. It's my fault,' because [Cody] was in my room, right?" Though they told her that was not the case, Amber confided she still—to this day—blames herself for her brother's injuries.

Emma also expressed guilt and shared, "[T]he thought that crossed my mind a lot growing up, is 'Why couldn't it have been me?'" As the older of the siblings Emma reasoned she may have understood better than her younger sister. However, she clarified this was a cognition she grew into and subsequently out of:

> I don't anymore, but I did for a while. I don't think I did right when it happened cause I didn't really understand guilt, but as I got a little bit older, it was "Why didn't I go down that side of that hill? Why didn't I make sure she was—why didn't I help her get out of the wagon and take her wagon up first and help her up the hill instead of taking my

tricycle up first?"….[I]t wasn't so much that I felt that I caused it…it was more things that

I could've done differently to make it less prominent or to have hurt me instead of her.

When Isabella was being hospitalized for wanting to harm herself Emma confided thinking to

herself, "It wasn't fair. Why did she have to feel that way? She's been through so much. Why

does she—why is her body doing this to her? Why couldn't it be me that is having this mental

breakdown?"

Conclusion. Michael was the only negative case for this particular theme. As previously

detailed, he was born after his sister's injury and did not express the same kind of adversity as

did the siblings who were alive at the time of and/or witnessed the injury. Instead he asserted:

Other than these little things here and there, I don't really know if it made a huge impact

on my life. Maybe it did more than I think it did, but I think that's a testament to my

parents and her…Just the way that they handled it and I never felt she got special

treatment. I never felt she was favored. I think my parents did a great job of handling

both situations.

When considering the pain and suffering settlement his sister received, he described it as

"lighthearted jealousy," and added, "She turned 18 and got this big old sum of money and she

got herself a new car and I was like, 'Dang it,' kinda thing, but it wasn't like I was angry or

jealous of her." In terms of feelings on burn camp he commented:

I never felt like, "Oh, I wanna go to camp with her." I think part of it was a lot of our

fallback and a lot of our childhood revolved around athletics and so it was always in the

summertime…We were both such active kids that I know I probably had my own camp.

All other participants experienced various emotions following the acute incident of a burn

injury, as well as during hospitalization, aftercare, and community/family reintegration. The

primary emotions articulated were anger/frustration, confusion, depression, envy/jealousy,

grief/loss, and guilt. Similar to their injured siblings' journey of healing and recovery, their

emotional evolution was a cyclical phenomenon; moreover, most communicated their feelings

culminated into acknowledgement and consideration with time and age. The next theme will

survey communication concerns.

Theme Four: Communication Challenges

All but one of the uninjured siblings articulated experiencing challenging communication

following the acute burn injury that endured through hospitalization, aftercare, and

community/family reintegration and promoted feelings of confusion, worry, uncertainty, and/or

angst. Communication was either nonexistent leaving the uninjured sibling in an information

vacuum and/or it came from indirect sources, such as other people providing secondary details or

them overhearing conversations. Specific concerns around communication were most frequently

articulated around emotionally processing the event/circumstance and basic injury details. Their

concerns were not just considered within the context of how others communicate with them, but

also how they in turn engage communication with others.

Nonexistent. Five of the participants expressed communication they generally perceived

as absent. When asked about conversations around feelings or emotion, such as guilt or anger,

Alyssa replied, "It's almost non-existent." Alyssa stated:

My dad, we don't talk about it. My dad's still very sensitive to it. My dad's this big ole

burly manly man. So, watching him cry, it sucks, so we don't talk about it. That's the only

thing that we've ever seen that would make him cry. I get it, he saved her. He's the one

who had to run into hell to get her.

Even when it comes to the communication with her sister, a relationship she perceives as a "bond," she acknowledged an inequity that was previously discussed within the context of her role as a protector. She admitted being a person her sister could open to but denied reciprocating her own feelings.

Amber also denied expressing any of her emotions following the incident, even up through the time of her interview. She detailed, "There's a lot, because I don't tell anybody anything so a lot of my family, what I went through, the guilt, how come I blame myself, that stuff is always there so I haven't really told anybody anything." She verbalized Cody is aware of the guilt she feels; yet, due to her own lack of comfort discussing the topic their conversation was cut short. She expounded:

> [T]here was one time we talked about it, but I cut it off. I just told him a little bit and then he knows a general little bit of how I feel because I talked to him once but didn't go through with the whole details because I got too worked up, yeah….[I]t's hard for me to talk about it.

Isaac similarly denied conversations about his thoughts or feelings following his brother's burn injury, including school or the financial settlement, with his family. Instead he perceived it as, "Hey, it's something we gotta deal with and we deal with it." He stated:

> My parents never really discussed…I feel like at the time I didn't really think about it that much, it was just me going through, but I feel like if it'd been asked, I might have told them the truth like, "Hey, this is how this makes me feel."

In terms of communication with his brother Isaac declared:

> Noah's also never been good with sharing how he feels at all. He doesn't know how to come up with the words to express a way that he's feeling. He's very, I guess you could

say anxious about discussing topics that kind of make him, I guess, unsettled. He's not really a person that you can have that kind of conversation with.

Even in terms of the incident itself, uninjured siblings were often left to wonder what exactly happened. After the hot soup spilled onto his brother, Isaac recalled:

Everybody just immediately got up and just left. I was left in there with my grandma and I didn't know what was going on. She kept saying, "It's going to be—it's okay. It's okay." Nobody ever really tell [*sic*] me what had happened.

When asked how he learned about his brother's injury or his understanding that something happened to his brother, Oliver replied, "Nobody talked to me about it….Not at all… Pretty much, they didn't communicate really well, my family. They were great pretenders like everything was okay all the time." He conceded, "I knew that he was burned by hot water… But I never knew any of the incident, I never knew any of that stuff until…probably when my brother would talk a little bit about it to people." After over five decades he is still piecing together information he overhears in conversations.

Oliver recalled his brother's return home from the hospital and him being wrapped up in bandages, something he described as "pretty brand new" to him and not knowing what happened. He assumed because he was 3 years old "[t]hey just felt like I didn't really need to know too much, I guess. Once I asked my mother, 'Why didn't you talk to me?' Her answer was, 'You were young, and we didn't want to upset you.'" Moreover, he remembered as a child having questions and wanting to inquire but feeling like he was not able to because "the adults were not comfortable talking about it." He recollected one specific incident when he was five and his brother was three. Scott returned home with his head completely bandaged after receiving hair

transplants. He walked into the kitchen and observed his brother's exposed head after Scott decided to remove all the bandages. He disclosed:

> I totally freaked out because his head was all bloody with all these little plugs everywhere and stuff. I can remember going in my room and hiding in the closet. I wouldn't come out. Yeah. Then, I remember nobody really talking to me about it, which was weird. There wasn't a lot of communication. Yeah, my parent's kind of struggled with—they didn't communicate well with each, other so they didn't communicate well with us as well.

Oliver recognized the communication style of his parents was likely a product of their own parenting. He explained, "[M]y mother came from those kind of parents where they weren't comfortable talking about anything that could be emotional," and added "I made them all very uncomfortable because I wanted to communicate all the time."

> After both of her sisters were injured in a camp fire incident and driven to the hospital by her parents, Ursala recollected her parents called her that night and told her she needed to stay with her friend's family, noting her sisters' injuries were serious. She continued:

> I didn't hear too much. I talked to my parents on the phone, but I wasn't able to talk to my sisters about what was really going on. I was kept in the dark a bit. They didn't tell me how much they were burned or what was really going on.

She asserted, "More communication would've been a lot better…Maybe there was less communication 'cause they were trying to shield me or shield Rose or—I don't know, but it seems like a lot more communication could've taken place." From an emotional standpoint, Ursala confided her older sister feels a sense of responsibility about the incident; however, she

noted, "I know she told me that, and she may have told Ruth that, but only once, and we never talked about it again."

Indirect. At times scarce communication provided opportunities for uninjured siblings to develop their own strategies for staying informed about their injured siblings. Alyssa detailed:

> [N]o one really wanted to talk to a three-year-old, so I was just piecing together information. Whoever had me at the time, they're always talking on the phone to mom, calling for updates and I'd pretend to be asleep. They'd be sitting there just talking all the way about it and that's usually how I found out. They talked to my brother a little bit more about it and he'd make sure to tell me about it.

At 5 years old Emma recalled understanding her sister "was hurt, very hurt" because "they didn't know if she was ever gonna be able to walk again." However, she presumed:

> I probably overheard my mom say it. My mom doesn't hide anything…She probably was talking to my dad at some point and mentioned that they didn't know if she was gonna be able to keep her legs. I may have overheard her and not fully understood, but I was probably aware of what was going on, at least somewhat, subconsciously aware.

However, piecing information together on their own or receiving varied messages did not appear to aid in their understanding any better than the absence of communication. Amber felt confused by the ambiguous messages received regarding her brother's prognosis following his injury. She recalled:

> [S]ome people were saying he was going to make it, some people were saying he's going to die, but, so it was a mixture of both that he was going to make it, going to die. At that age, I didn't know what to expect.

Conclusion: Unlike the participants noted above, Michael denied perceiving the burn injury as off topic or concerns around communication. He declared, "As far as the accident, this is why I feel I know, not to a T, but I know exactly what happened to her." Therefore, he is the only negative case located in the data. He continued:

> It wasn't taboo to talk about. I think my parents wanted us to be aware of how fortunate we were…[I]t was sad. They always had eventually gotten to tears because they talk about that day and it brings back all the emotions. It was a sad day, but yeah. It was never hard to talk about as a family.

Though, he also acknowledged:

> [O]ne of the things that was off topic was I know that there were pictures. I knew when I was at a young age that there were pictures of her injuries and of course they were pretty graphic, and I didn't get to see those pictures until I was a senior or my freshman year at college.

All other participants articulated examples of communication that was either nonexistent and/or indirect, particularly within the context of emotionally processing the event/circumstance and basic injury details. The absence of communication or processing of ambiguous messaging sustained some of the revolving emotions discussed in the previous section, especially confusion and guilt. Additionally, these communication concerns persisted from acute injury through hospitalization, aftercare, and community/family reintegration. Several uninjured siblings indicated that even after all these years there remains a lack of open dialogue. The final theme discussed will be identity through autobiographical reasoning.

Theme Five: Identity through Autobiographical Reasoning

By advancing interpretative or reflexive processes all uninjured siblings articulated self-growth by emphasizing how past events played a contributing role in developing their sense of self (McAdams, 2018; McAdams & McLean, 2013). The ability to advance a life story, or narrative identity, begins to develop in late adolescence via autobiographical reasoning (Habermas & Bluck, 2000). Autobiographical reasoning is defined by Habermas and Bluck (2000) as "a process of self-reflective thinking or talking about the personal past that involves forming links between elements of one's life and the self in an attempt to relate one's personal past and present" (p. 749). Within the context of these findings it is conceptualized as two themes of growth—identity clarity and mean-making—that are not always mutually exclusive (Lilgendahl & McAdams, 2011; McLean & Thorne, 2003).

As outlined in Lilgendahl & McAdams (2011), identity clarity is defined as "the development and clarification of identity-defining goals, beliefs and values" (p. 5) (Erikson, 1963; McAdams, Hoffman, Mansfield, & Day, 1996); and meaning-making is thought of as what is learned or understood from a past event (McLean & Thorne, 2003). Meaning-making is further differentiated by the depth of consideration into either lesson learning or gaining insight (McLean & Thorne, 2003). Lesson learning is thought of as an explicit example that might guide upcoming behavior; whereas, gaining insight considers the impact beyond a specific behavior and frequently includes an alteration in understanding of the self and/or relationships with others (McLean & Thorne, 2003).

Identity clarity. All of the uninjured siblings articulated ways their sibling's burn injury contributed to their understanding of how they define themselves, as well as developing their sense of purpose in life. As summarized by Lilgendahl and McAdams (2011) identity clarity is

generally conceived as "the content of what makes you who you are—e.g. choice of career, ideological beliefs and values, etc.—and the feeling of knowing yourself and the direction or meaning of your life" (p. 10). For example, as explained earlier during the description of the artifact she chose to illustrate her sibling relationship, Alyssa articulated her sense of purpose:

> [M]e and Tiffany complement each other well. I'm the one that helps her and she's the one that needs help, but Tiffany gave me that purpose as a sibling. She gave me the purpose to be helping and it just shows how our relationship just worked. Tiffany needed help, I was there. Tiffany gave me a purpose to be there.

Aside from identifying her purpose as being there to help her sister, Alyssa also expressed identifying as independent and acknowledged that when it comes receiving help, "I'm not very good at." She explained:

> Being the kid that wasn't burned, you had to become very independent because your parents really needed to focus on them [the injured sibling]. Building that independence for myself and, if anything, having everything taken away from you, you're going to keep whatever you can. Keeping that independence is something that meant a lot to me and someone helping me would take that away.

Moreover, Alyssa confided she is guarded and finds it challenging when it comes to allowing others to get to know her and her story. She clarified:

> Everything becomes about them [the injured sibling], so does your life. So when people try to get past them and into your life, that's where you come out of your comfort zone because—and that's one thing that I struggle with—people try to get to know me and I end up talking about Tiffany, talking about everything else. I don't know how to let them get to know me because Tiffany's story became my story. After a while, I had to learn to

build my story and figure out what my story was because, as much as I wanted it to be

that way, that's Tiffany's story.

Alyssa explained her "want[ing] it to be that way" meant it was easier "to hide behind

[Tiffany's] story so people didn't ask how [she] was and what [she] thought about it." She

asserted that if people tried to get to know her she would have to tap into her own feelings, such

as anger, anxiety, and fear; and, she did not want to position her story as a comparison

"[b]ecause people would always see Tiffany's case is worse."

Furthermore, her experience produced clarity around career paths. She recalled thinking:

I'm going to grow up to be a firefighter. I'm going to be the first woman firefighter if I

want to be…Because I'm going to save that kid. That kid that reminds me of my sister,

I'm going to save them. I'm going to give them a better chance and I'm going to get to

them before the fire does.

Though she spent a number of years on track to become a firefighter, including participating in a

fire service explorer program, Alyssa shifted into another vein of public service becoming

employed as a 911 dispatch officer.

Amber also expressed how she perceived the experienced altered her as a person. She

detailed, "It made me a better person. More willing to help people who's [*sic*] in need because I

needed help." However, she voiced her life became challenging early on when, at the age of 10

years old, she reported her mom "walked out" on the family. She expounded that her mom's

absence from the family, which positioned her as the eldest sibling, established her heightened

sense of personal responsibility—verbalized as a "huge burden"—to her four younger siblings.

Therefore, as the oldest sibling, she assumed a maternal role that reinforced her subsequent

enhanced sense of blame when Cody was injured. Moreover, between her mom's absenteeism

and her brother's injury—situations not causally related nor easily disentangled—Amber related the following as her sense of self:

> [S]omeone who's struggled all of her life. Never had anybody there for me. When I try, they pushed me away, so I was pretty much on my own, the outcast—doing everything on my own… except my aunt who was there who passed away, but other than that, it was me just trying to get by in my life.

At 18 she moved out of the family home and confided:

> [T]hat's when I got into some bad habits just because of everything I went through with raising Cody and my siblings, going through the fire. Got in some bad habits, cleaned myself up, went to school, graduated school, went to nursing, got my healthcare aid. When people said I wasn't going to graduate, going to have kids when I was young, so I proved all that wrong. Pretty much fought for everything I have right now.

She indicated the support her brother received following his injury compounded her professed trials and tribulations, "He was lucky to have people there helping him out for school, for everything so he was lucky to have the life he has right now," and reiterated her experience that "no one was ever there for me."

Emma recalled a conversation with her dad after Isabella was injured and how it impacted her religious views. She detailed her parents attended church routinely prior to her sister's injury and then after they ceased going. Emma asked him why and explained, "[T]his whole incident made him lose his faith cause if there is a God, why would God let something like this happen to such an innocent little child?" It was a profound moment in her childhood. She affirmed:

That stuck with me and still has to this day. It's part of the reason that I've questioned my faith, is because, yes, if there is a God, why? Why her? Why such a small child? Just why? I think that's the most important conversation that I've ever had with my dad in regards to Isabella's injury.

Her mom has not taken the same definitive position as her dad when it comes to faith. Instead, Emma noted her mom is "on and off again, on and off again, on and off again." She noted, "[H]aving a parent that can't make up their mind about whether or not they believe there's something makes it hard on me, or hard on the children as to, 'Well, is there something?'" She found the dearth of her parents "straightforward faith" and her mom's erratic involvement with religion confusing. Emma concurred that her family's experience with her sister's injury "definitely" shaped her religious/spiritual views and emphasized it was not just because her parents' view changed, noting "[I]t also changed the way I view about [*sic*] it, too, because I've been through the same thing. If there is a God, an all-powerful being, out there, why did he let this happen?" Therefore, she voiced her religious beliefs as follows:

> My position has been there's no proof. I believe that there's something out there, but I don't believe that it's anything that we could know about. Maybe there is a God, but I don't think that the Bible or any of that stuff is accurate because how would we know? How do we know what happens after we die? There's no way to know. I think that if you want to go to the better place when you die, live a good life. Don't do things that are wrong, like don't go killing people. Don't go stealing from people.

Similar to Alyssa, Emma conveyed precision with regard to her professional interests that were influenced in childhood and expressed a deep-rooted desire to work with kids. She explained, "I think part of it has to do with (a) I didn't really get a childhood, but, (b) I know

kids. I know how to interact with them, and I'm good at it." Initially, she considered being a teacher, but subsequently learned it may not be the best fit for her. She also considered becoming a therapist in order to "help people the same way they've helped [her]." However, she later decided, "I couldn't handle that. I couldn't handle taking in other people's problems on top of mine and balancing it all out. I just couldn't do it." As a result, she is still evaluating other options for career choices moving forward.

Isaac identified himself as a "huge gamer" and argued Noah's injury "really kind of jump started me as being a gamer." Noah was unable to go outside for a while following his burn injury, which altered the brothers' activity options; thus, Isaac recalled they began to play video games—an activity they still enjoy together as adults. He reasoned that without Noah's outdoor activity restrictions "I wouldn't have really been introduced to [gaming] at that young of an age and just make that, basically, my whole life at this point." However, he reflected, "It kind of made us introverted. Around other people that weren't gamers, as kids it was really kind of—we didn't have the social skills all there because we spent so much time playing video games," which he further explained as "something you get with a lot of gamers." He concluded, "I'm a very solitary person for the most part, I guess, because of my gaming habit and everything like that. I kind of established who I am today." Aside from becoming a part of his identity, Isaac attributed the online community as his source of relationship building. He stated, "[T]hat's where I basically established all my friendships. All my friendships are with gamers and they're a lot like me being introverted, which I've come out a lot."

Isaac described himself as a "[g]amer that has a dead-end job and just works and goes home and does nothing, pretty much." Similar to Amber's sentiments that her brother had access to resources she did not following his injury, Isaac posited the financial settlement his brother

received from the restaurant created in an inequity in opportunities, particularly when it came to education. He defined his options as "[p]retty much non-existent." He acknowledged his future was something he did not consider until after high school when he worked several jobs at one time and admitted, "I didn't have the greatest grades in high school….I knew if I was going to college it was going to be something lower like a tech school or something. I completely gave up on university." Once he decided he was ready to attempt his hand at college, he reported difficulty securing financial aid due to family circumstances. He is currently in a manual labor position and related, "I don't see myself making a lot of money in the future unless I get out and go try something, which I've been considering the prospect of trying to start college, maybe doing online courses….Something with computers, probably."

Meaning-making. McLean and Thorne (McLean & Thorne, 2003) posit that "meaning refers to what one gleans from, learns, or understands from the event" (p. 636). According to Pillemer (1992), meaning-making involves taking that one step farther to suggest that what was inferred from considering the experience yields connections on future behaviors, beliefs, and the self. McLean and Thorne (2003) argue this can be further distinguished by thought complexity beginning with lesson learning and advancing into gaining insight as the superior classification. Following the same practice as McLean and Thorne (2003), if uninjured siblings suggested a transformation of self or relationship that pertained to greater areas of life it was considered gaining insight. All uninjured siblings articulated higher order meaning-making—or gaining insight—as they reflected on their narratives. However, a few examples of lesson-learning will be discussed before advancing into data to highlight gaining insight.

Lesson-learning. Simply stated, lesson learning was characterized by an uninjured sibling expressing a specific lesson they learned from their memory of the experience and how

that knowledge could direct their behavior in comparable future circumstances (McLean & Thorne, 2003). Alyssa recalled her experience meeting another uninjured sibling at a weekend program and how she and the girl exchanged stories and shared experiences. She detailed from that conversation she learned "[h]ow to be a counselor to other siblings, just being there for people. I enjoy it, just watching the look on their face when they actually get to say what they want to say without being discarded." She concluded, "Being able to counsel is the best thing that I've learned." Michael had the opportunity to meet other injured children through his participation in the family day program at the burn camp his sister attended. He reported becoming attuned to varied burn injury experiences and asserted, "Disfigurement is terrible. Nobody wants to be looked at or stared at," and thus noted a changed way of engaging with others—albeit difficult at times—he met that may have cosmetic changes.

Gaining-insight. Broadening the scope, gaining insight was considered when uninjured siblings expressed what was understood from their memory of the experience as relevant to a larger scope of life, often alongside a transformation in knowing oneself or their relationships with others (McLean & Thorne, 2003). When Michael considered the experience endured by his sister, a situation he was born into he explained, "I think we always chose to look at the brighter side of you know but be aware of the darker side. We were always pretty aware of how fortunate we were." Alyssa articulated a newfound awareness after the family worked through the loss of their home and the acute injuries of both Tiffany and their dad. She clarified, "[W]e realized what can and can't happen and it just made us, we're just a really close family." Similarly, after reflecting on the entirety of his story Isaac detailed:

[I]t's so easy how life…just one thing in life can alter the entire course and, even if it didn't even directly happen to me, it set in motion a series of events that lead to me being where I am today.

Ursala considered herself fortunate as the only sibling who was not injured in the campfire accident, realizing she was potentially one decision away from also being injured. She recalled, "Thank goodness I was in the tent. I could've gotten up, too, and I could've been just as burned as they were." Reflecting on what she gained from her experience she offered:

I just think that what maybe I can take away is that everyone is a lot stronger than they think they are because I'm sure when it first happened, we thought, "What is gonna become of us?" or "What's gonna become of her for having to endure all of that?"…Probably just overcoming all of that and the strength that it provides.

Oliver evoked an experience in school where a bunch of kids cornered Scott and tried to pull off the stocking cap that was covering his bandaged head following a recent surgery. Oliver disclosed how helpless he felt adding, "I couldn't do anything to help him. I remember that." Though he acknowledged his own insecurities at that time, he recognized the helplessness was more than a product of those uncertainties. Instead, he conceived:

I guess what happens is that, I haven't really thought about it, but probably if I would have been in a healthier family that communicated better, I might have been stronger to help him, yeah, but I felt pretty disempowered, yeah, a lot of times and powerless, yeah.

Amber attended the World Burn Congress with her brother a few months before her interview for this study and proclaimed, "It was probably one of my best experiences ever." This was a firsthand opportunity for her to engage with others whose lives had been altered by a burn trauma. As a result, she detailed the following awareness:

I got to meet so many people who was [*sic*] actually worse off than my brother…I've seen one [injured individual] for example, with his fully [*sic*] burns and hopping around with his one leg, one arm, jumping around, having a time. They're so positive that when I came back it made me realize that my life's not so bad, but if you stay positive, good things will happen.

When Emma and her dad had the conversation about his transformed religious views following Isabella's injury, she also described how she became aware of the guilt her dad was feeling. She explained, "He talked about his guilt at that point, because, again, I was a little older, so I understood a little bit more what guilt meant." Additionally, she expounded on another relevant insight:

Around that time, I started to realize how it affected my parents, cause up until then it was just how it affected me and her. At that point, I realized, "Oh, it's not just me and her. It's everybody. It's our family. It's the neighbors. It's the community. Everybody's affected."

Enduring the difficulties following Isabella's injury and years of hardship related to mental illness in the family, Emma posited the following:

I do not have a normal family…I don't think it's bad anymore. I used to think it was bad. I think that we're different, and we're different and that makes us unique. It has impacted who we turned out to be, but I don't think it's a bad thing anymore…having a family that has so much going on in terms of Isabella's accident and a mental illness. Mostly that stuff.…It makes us unique. It makes us who we are.

Conclusion. From this data a negative case was not located. A negative case could be a participant who was not able to find any meaning from the past experience or how it relates to

their present identity and/or self-growth. However, all participants in this study were able to articulate a sense of self and/or self-growth through autobiographical reasoning, including their choice of careers or professional interests, ideological beliefs, religious beliefs, values, and a general sense of self awareness and purpose. Furthermore, uninjured siblings narrated multiple examples of ways they created meaning from their experience as both lessons learned and insight gained.

Chapter Summary

This chapter offered a detailed exploration of the five themes that were identified across individual experiences, or participant stories. The five overarching themes that were reviewed included: 1) separation and alternative caregiving, 2) altered interactions and ambivalent roles, 3) (r)evolving emotional pain, 4) communication concerns, and 5) identity through autobiographical reasoning. Several themes additionally included sub-themes that further contextualized the experience of growing up with a sibling who experienced a burn injury in childhood. However, as previously argued, it is important to consider distinctions in their uniquely individual narratives. The findings outlined in Chapters 4 and 5 highlight the importance of consideration for uninjured siblings following a sibling burn trauma. They also make an argument for increased attention for the development/enhancement of programs and services to mitigate additional trauma and hardship following the acute disturbance. Yet, it is also encouraging to note that through the disruption and disconnection of their sibling's burn trauma, uninjured siblings were able to articulate how their past experience played a role developing their sense of self, though it can be dichotomous. The final chapter will provide a summary and discussion of the findings, as well as implications for social work practice, and close with recommendations for further research.

CHAPTER 6

DISCUSSION, IMPLICATIONS, RECOMMENDATIONS, AND CONCLUSIONS

Introduction

The previous five chapters provided: 1) a brief introduction to the study, including a

statement of the problem, purpose of the study, presentation of research questions, theoretical

frameworks, study significance, and definition of key terms; 2) a review of literature pertinent to

understanding burn injuries, their location in the literature, the burn community, previous

research for families and siblings within the context of the burn injury experience, and

interventions; 3) an outline of the research methodology, including a subjectivity statement,

research design, methodological and theoretical frameworks, methods of data collection and

analysis, strategies to assess data quality, and methodological limitations/critiques; 4) research

findings presented as detailed stories for each participant, including brief artifact descriptions (if

provided), and a metastory; and 5) research findings discussed as themes identified across

individual experiences. Chapter 6 serves as the final chapter and will begin with a brief review of

the study's purpose, research questions, methodological and theoretical frameworks, participant

information, and summary of findings. It will then provide discussion, limitations, implications,

recommendations and conclusions.

The purpose of this study was to understand the experience of growing up with a sibling

who experienced a burn injury in childhood, with attention to how their identity was shaped. The

scant research exploring this through a qualitative lens facilitated the opportunity to consider

these stories—or narratives—via direct accounts from uninjured siblings as experts in their

experience. The unique accounts and overarching themes shared by adults engaging reflectively about that component of their history permitted a dynamic and integrative perspective, as well as identity inferences. The research questions that guided this narrative inquiry were:

1. What are the experiences, or stories, of identified adults whose sibling experienced a burn injury?

2. What do the narratives of identified adults whose sibling experienced a burn injury reveal about how their identities were shaped?

3. What are the implications for program/service development and/or enhancement elucidated by identified adults whose sibling experienced a burn injury?

The theoretical frameworks that guided this narrative inquiry were social constructionism and narrative identity. Social constructionism recognized the importance of understanding the world in which the uninjured siblings lived while appreciating these accounts were there *their* interpretations—not *the* interpretation—co-constructed through our interactions at the point and time of our interviews, as well as during the process of analysis. One of the strengths of social constructionism as a framework is that is allows multiple equally valid realities over one single truth. This study was about seeking to understand the reality of uninjured siblings from their perspective and their perspective alone. These detailed stories facilitated elucidating implications on their life and their identity through the lens of narrative identity. This framework further informed the study by acknowledging the self is a story—one that is internalized and evolving—and through the ongoing process of reconstructing the past and imagined future—or formulation of one's story—individuals are able to integrate, or make meaning, about what their story means concerning their purpose and identity.

This narrative inquiry included data from seven participants—four females and three males—that through purposeful criterion sampling, and later sequential and emergence-driven strategies, were interviewed either in person or via technology assisted techniques. Interviews ranged in duration from 59 minutes to 105 minutes. In addition to interviews, participants were also asked to provide an artifact they felt represented their relationship with their sibling either before, during, or after the burn injury. Based on criteria established to assess burn injuries, seven of the eight siblings who experienced burn injuries had wounds that were classified as either major burn injuries or injuries that should be treated at a specialized burn center.

Summary of the Findings

The findings were presented in two chapters. First, in Chapter 4 as detailed accounts for each participant—including images of artifacts provided for inclusion in the study and brief descriptions—as well as one overall metastory, or hybrid account, as a representation of all participant experiences. Next, in Chapter 5, overarching themes were identified across individual accounts that included: 1) separation and alternative caregiving, 2) altered interactions and ambivalent roles, 3) (r)evolving emotional pain, 4) communication concerns, and 5) identity through autobiographical reasoning. The themes were not meant to dilute the nuances of participants detailed accounts or be indicative of a comprehensive illustration, but instead to provide a way to capture key similarities or commonalities between and amongst stories, acknowledging participants may not encompass all aspects. The data suggest that uninjured siblings have their own unique narratives that have failed to be acknowledged within the context of both research and practice, though all articulated identity clarity and meaning-making in their reflections. Furthermore, findings support the consideration of many of their experiences as a primary trauma. These results create space to argue the critical need to expand consideration—

specifically as it relates to inclusion, identity, and resource acquisition—within the context of the burn community, in order to provide more comprehensive program/service development and/or enhancement.

Discussion

This narrative inquiry was the first study to consider the experiences of adults whose sibling experienced a burn injury and elucidate compelling detailed accounts of their individual stories with attention to how their identities were shaped. The previous three studies that investigated the uninjured sibling's experience were conducted over a decade ago (Conroy, 2008; Lehna, 2008, 2010), with the preliminary research taking place over 15 years ago (Mancuso, 2002; Mancuso et al., 2003). The studies reported methodological challenges that warranted the utilization of a qualitative approach and also suggested inconsistent findings (Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003). These three studies provide the only foundation for knowledge around the uninjured siblings experience; yet, these pioneering researchers clearly articulated further research was warranted. Narrative inquiry provided a meaningful way to fill some of these gaps in knowledge.

The first research question involved addressing the question, "*What are the experiences, or stories, of identified adults whose sibling experienced a burn injury?*" The detailed accounts outlined in Chapter 4 suggest that uninjured siblings have their own unique story with identity implications regarding their experience that to date appear neglected in both the literature and practice. Additionally, four of the seven participants directly reported this was the first time anyone asked about what the experience was like for them or how they perceived the burn injury contributed to their story. Though it was the first time for many to share their story, they did so with an ease, some expressing a sense of relief regarding articulating their emotions and

experiences and confided emotive responses when they read their own stories during member checking. It would be naïve to think there was something extraordinary about the interview questions; instead, similar to what Dillard and Kolomer (2019) suggested regarding their examination on parenting burn injured children, I believe their experience further highlights the obscured narratives of uninjured siblings that is consistent with the scarcity of inclusion in both research and practice.

Furthermore, the individual accounts and metastory not only support the argument that uninjured siblings have their own unique story in the experience, but moreover, these are narratives that entail their own primary trauma (5th ed. DSM-5; APA 2013), whether in response to directly witnessing their sibling's physical injury—which was the case for five of the participants—or subsequently learning about the traumatic injury of their sibling. Also, it appears the traumas—endured throughout acute incident/hospitalization and post discharge/ongoing medical treatment—have not only gone unacknowledged but have been managed autonomously by many of the uninjured siblings. Exposure to trauma in childhood is not a unique experience (Copeland, Keeler, Angold, & Jane Costello, 2007; Landolt, Schnyder, Maier, Schoenbucher, & Mohler-Kuo, 2013; McLaughlin et al., 2013) and has the potential to impede many aspects of healthy adult functioning; yet, interventions and/or policies that target childhood trauma have the potential to enhance the long term health and well-being of children (Copeland et al., 2018).

Though stories are found to provide comfort and a median for coping in the wake of traumatic life events (Jirek, 2016; L. A. King, Scollon, Ramsey, & Williams, 2000), these findings beg the questions: 1) What happens when—such as the case for many of these participants—there is an absence of opportunities or outlets to share experiences or emotions? and 2) When attempts are made to confide in others the experience is minimized or ignored? For

Alyssa, this resulted in banishing herself to an "island" where she shut down due what I refer to as an emotional embargo or arguably emotional neglect—though not in malice. In 1998, adverse childhood experiences (ACE) (Anda et al., 2006; Felitti et al., 1998)—emotional abuse, physical abuse, sexual abuse, emotional neglect, physical neglect, mother treated violently, household substance abuse, household mental illness, parental separation or divorce, and/or incarcerated household member—were documented in a collaborative research project between the Centers for Disease Control and Kaiser Permanente that created momentum for a major paradigm shift regarding the medical community's approach to disease (American Academy of Pediatrics, 2014). The study documented ACE can considerably contribute to negative physical and mental outcomes for adults (Felitti et al., 1998). Though some stress is inevitable, even developmentally appropriate, prolonged engagement and activation of the body's stress response system has devastating results that can endure a lifetime, with implications on learning and behavior, as well as both physical and mental health (Shonkoff et al., 2012). Furthermore, findings suggest that the results of earlier trauma on the adult stress response system can minimize their capacity to manage stress in a healthy way and increase social risk factors in both childhood/adolescence and adulthood (American Academy of Pediatrics, 2014), which was exemplified through one of the participants disclosed challenges with alcohol/substance use (Lown et al., 2013).

However, injured siblings frequently had access to resources, particularly burn camp, discussed in both the literature (Bakker et al., 2011; Cox et al., 2004; Maertens & Ponjaert-Kristoffersen, 2008; Maslow & Lobato, 2010; McShane et al., 2000; Rimmer et al., 2012; N. R. Williams et al., 2004), as well as anecdotally in this study via uninjured siblings' narratives, which indicate the benefit these programs provide injured siblings following their burn trauma. According to Bastian and Haslam (2010), "Humans have a fundamental need to form and

maintain relationships" (p 107). Several of the siblings in the study articulated they wanted to attend the burn camp program their injured sibling participated in out of the inherent desire for inclusion in a community, as well as a fundamental awareness they were missing out on fun. Two explicitly expressed their desire to share in the experience so badly that they recall thinking—one even articulating to a camp volunteer when she was a child—they wished they had been burned so that they could join the camp. These sentiments were also echoed in the cancer literature by healthy siblings (Tasker & Stonebridge, 2016) who were not included in programs/services for their siblings with cancer. These statements are profound and suggest their desperation to have a space to seek solace and inclusion. It challenged me to give pause and consider the notion that although burn camps have been a worthwhile resource for children who have experienced burn injuries, how many uninjured siblings have been ignored and diminished along the way?

In addition to several participants feeling isolated and discounted by a lack of inclusion in the resources provided to their injured siblings, all but one of the participants also narrated the experience of being separated from both their injured sibling, as well as their parents, often for extended periods of time during the acute phase of injury treatment and aftercare, which added to their sense of isolation and disruption. This is consistent with previous findings for siblings of children with cancer and cystic fibrosis who also experienced challenges related to separation as a result of their ill sibling (Murray, 1995, 1999, 2000a; P. D. Williams et al., 2009). Dillard and Kolomer (2019) reported parents also struggled with being separated from their uninjured children but felt conflicted on how to manage the situation and competing demands. Feeling socially isolated or excluded has been found to be a dehumanizing experience that has the potential for individuals to minimize their own attributes (Bastian & Haslam, 2010). Moreover,

mental or emotional isolation has implications on depression and suicidality (C. A. King & Merchant, 2008; Qualter, Brown, Munn, & Rotenberg, 2010), which were experiences also articulated by several participants in this study.

Congruent with earlier research for pediatric cancer (Björk et al., 2011; Nolbris & Ahlström, 2014; West et al., 2015), juvenile arthritis (Waite-Jones & Madill, 2008), and siblings with burn injuries (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002; Mancuso et al., 2003), uninjured siblings in this study also expressed a sense of disorder to their "normal" sense of routine. Participants communicated this as not only a result of the separation from their parents and siblings due to the parents sustained need to be with their injured child, but also through alternative caregiving—often away from their own home—verbalized by a number of participants that heightened their sense of disconnection and disruption. This appears to be a new, though understandable, theme discussed within the context of uninjured siblings' experiences following a burn trauma due to the abrupt and acute nature of burn injuries. The uninjured siblings' narratives also suggest that it was not uncommon for the alternative caregivers to be individuals that their parents did not know very well—even if it was just temporary.

Moreover, one participant disclosed an unfortunate abuse that happened while staying with someone known to the family. Though it was addressed with the proper authorities, to date it is still not openly discussed in the family out of a sense of inoculating the injured sibling from what her uninjured sibling perceives as guilt and personal responsibility for the disruption to the family's life; yet, it remains unclear the long-term impact of this for both the family and sibling dynamics. Additionally, it provides another illustration of the uninjured siblings needs being minimized. Lastly, two participants' experiences were compounded by the complete loss of their

family homes, in addition to separation from their family, disrupted routine, and alternative

caregiving. This particular etiology of grief and loss has been argued as an area that is often

overlooked (Morad & Morad, 2017), but a deeply personal trauma where an individual's house

takes on symbolic significance as an extension of oneself (Lollar, 2010).

Though not previously explored within the context of burn injuries, findings suggest

further support of Burke's (2004, 2007, 2010) framework of "disability by association."

Uninjured siblings in this study indicated an inequity of parental treatment—both time and

resources—as a result of their injured siblings contending and often overwhelming needs (Burke,

2004, 2010), which diverged from earlier research regarding uninjured siblings' experiences

following a burn injury. Specifically, none of the uninjured siblings within this scope of prior

research verbalized differential treatment (Conroy, 2008; Lehna, 2008, 2010; Mancuso, 2002;

Mancuso et al., 2003). However, Conroy (2008) acknowledged they could have felt this way, but

just did not explicitly verbalize their feelings. Mancuso (2002) also reported conflicting

comments from uninjured siblings that their parents did too much for their injured sibling.

However, findings from this study are consistent with challenges regarding parental treatment

and attention that are well supported in other domains of sibling research around illness and

injury (Alderfer et al., 2010; Tasker & Stonebridge, 2016; Tyerman, Eccles, Gray, & Murray,

2018; Waite-Jones & Madill, 2008; Weiner & Woodley, 2018), that suggests the adverse

implications differential treatment can have on the sibling relationship (Long et al., 2013;

Scholte, Engels, de Kemp, Harakeh, & Overbeek, 2006; Shanahan, McHale, Crouter, & Osgood,

2008), particularly younger same sex siblings (Scholte et al., 2006).

Additionally, uninjured siblings in this study spoke candidly about their experience of

responding to questions and comments about their siblings' injuries, in addition to observing

"stares" from others (Lehna, 2013). At times this entailed many of them altering their own relationships or engaging new, sometimes ambivalent roles, with both their injured sibling and others that heightened social isolation. Lehna (2008, 2010) also reported—though participants did not discuss in great depth or detail—that uninjured siblings commented on having to manage questions, stares, or comments in response to others about their sibling's burn injury. One of the roles uninjured siblings in this study assumed was that of a social advocate or protector, either physically or verbally (Lehna, 2013). They also operated in a protective role by opting out of activities or peer groups who were not inclusive of their injured sibling, which extended their experience of exclusion and isolation. Research indicating siblings operate in a protective capacity (La Clare, 2013; Nolbris et al., 2007; Orange, 2014; Waite-Jones & Madill, 2008) is supported in the literature. Additionally, uninjured siblings operated in a caregiving position congruent with prior research (Burke, 2010; Tasker & Stonebridge, 2016). However, due to the nature of burn injury treatments discussed earlier (i.e. wound cleaning and physical/occupational therapy), participating in caregiving either directly or indirectly frequently provided additional trauma to the uninjured siblings in this study, with several noting nightmares (Nolbris & Ahlström, 2014) or triggers to certain stimuli.

In terms of communication, only one participant in this study articulated interaction from his parents that was direct and approachable. Other participants suggested a desire to understand more about what was happening with their sibling's injury, the changed family routine, and emotions; yet, information about the specifics of their siblings' condition or family circumstance was often either not received or gathered indirectly. Moreover, conversations about their emotional well-being was almost non-existent. In contrast, the first study exploring uninjured siblings experiences following a burn injury, suggested that uninjured siblings denied discomfort

talking about the burn injuries with their parents (Mancuso, 2002; Mancuso et al., 2003).

However, other inquiries with populations of ill/injured siblings reported consistent findings that

frequently posited healthy or uninjured siblings felt confused, uninformed, and/or longing for

more direct and honest communication (Haverfield, 2016; Tasker & Stonebridge, 2016; Waite-

Jones & Madill, 2008) and would benefit from increased dialogue (Burke, 2004; Gullick et al.,

2014). Nonetheless, at times uninjured siblings in this study also acknowledged they

intentionally refrained from initiating conversation or withheld emotional exchanges with their

families and/or sibling as another attempt to guard them from further hardship even though it

was at their own emotional expense (Gullick et al., 2014). Though several participants in this

study articulated apprehension or angst around conversations that they perceived as challenging

or uncomfortable, research suggests there is frequently more to gain by engaging a difficult

conversation then maintaining an avoidant attitude (Keating, Russell, Cornacchione, & Smith,

2013). Furthermore, communication that allows for a more fully advanced understanding of

diagnosis/condition and the family circumstances promotes a more integrated experience with

increased role clarification (Plumridge, Metcalfe, Coad, & Gill, 2011).

The experiences articulated within the narratives of uninjured siblings in this study

appear to fit within Burke's (2004, 2010) framework of "disability by association." Most

participants articulated changes within their family system, that frequently led to experiences of

isolation and neglect at home—though again, not seemingly intentional. Furthermore, within the

context of their social environment, uninjured siblings frequently found themselves responding

to questions, comments, or stares from others and at times even altered their own peer groups or

activities in attempts to protect their siblings, which created space for increased social exclusion.

Burke (2004, 2010) discusses this notion of community interactions as occurring primarily

within the peer group or school environment. Yet, it is worth noting that participants in this study often discussed feelings of social exclusion with programs/services that served as resources for their injured sibling (i.e. burn camp). Additionally, one of the siblings expressed multiple examples of how she felt her experience was explicitly minimized, not just overlooked, by others following the incident. This emotional embargo, which appears to endure in adulthood, along with the experiences discussed above, suggest support of Burke's framework within the context of burn trauma as "burned by association" or even "burned by (dis)association." Though further research is warranted to understand, support, and expand upon this concept, it can potentially strengthen the argument for increased attention in the burn community.

Burke's (2010) concept of "disability by association" is not meant to suggest associative identities are only considered through the lens of negative associations or outcomes but also provide opportunities for advocacy and empowerment. All participants in this study verbalized ways they similarly felt empowered by caregiving, advocating and/or protecting their injured siblings, as well as educating others about burn trauma, in addition to their increased capacity for compassion and appreciation for the fragility of life. The potential for growth and resilience are supported in the literature within the context of illness, disability, injury and trauma (Bonanno, 2005; Burke, 2010; Dekel, Mamon, Solomon, Lanman, & Dishy, 2016; Fazio & Fazio, 2005; Hooper, Marotta, & Lanthier, 2008; Janoff-Bulman & Frantz, 1997; Janoff-Bulman & Frieze, 1983; Mancini & Bonanno, 2006; McCormack & Thomson, 2017; Park & Ai, 2006; Ramos & Leal, 2013; Tedeschi & Calhoun, 2004; Weiner & Woodley, 2018). Therefore, the discussion will now shift to understanding implications on uninjured siblings' identity, explored within the context of self-growth.

Specifically, the second research question investigated the following, "*What do the narratives of identified adults whose sibling experienced a burn injury reveal about how their identities were shaped?*" The seven narratives explored in this study allowed the first opportunity to glean an understanding around how their identity was impacted by growing up with a sibling who experienced a burn injury in childhood. As noted earlier, most of the participants were new to sharing their stories, which suggests their lack of inclusion and the minimization of their part in the burn injury experience; yet, research also supports that individuals are less likely to discuss events they perceive as negative or emotional (Pasupathi, McLean, & Weeks, 2009). Therefore, though there were noted voids of available opportunities or encouraging environments to converse, this finding suggests an additional point to consider.

It was not just the retelling of these stories that provided insight, but rather how participants interpreted and grew from these prior events and details by connecting their stories to their past, present, and future selves (Habermas & Bluck, 2000; McAdams & McLean, 2013). These narratives essentially served as a reflection of their identity at the point in time of the study, with an understanding they are likely, by the very essence as their narrative identity, to evolve over time (McAdams et al., 2006). By adulthood most individuals have endured countless positive and negative life encounters. However, it is not an individual's present-day feelings or attitudes that are tied as closely to what actually happened in the past, but rather how they have chosen to incorporate these parts of their life into stories of self-growth, while also recognizing the transformative capacity gained from negative incidents (Lilgendahl & McAdams, 2011). As previously detailed, all of the participants in this study were able to articulate growth from their experience via either identity clarity and/or gaining insight—a higher order of meaning-making.

When it comes to trauma and its impact on meaning, Janoff-Bulman and Frantz (1997) argue that the foundation of our cognitive-emotional systems are basic models or theories that help to guide interactions in the world. Specifically, these involve assumptions about ourself, the external world, and the relationship between the two (Janoff-Bulman, 1992). Or in other words, the self is worthy, the world is benevolent, and the world is meaningful (Janoff-Bulman, 1992). However, trauma and other disruptive events—such as a burn injury to a sibling—shatter these assumptions and as such plague individuals with fear and anxiety and create an innate and heightened awareness that it is possible for bad things to happen them (Janoff-Bulman & Frantz, 1997). Consequently, these events often lead to "'value'-ation, or rather re-evaluation" of one's life in order find ways to create significance or worth in one's existence (Janoff-Bulman & Frantz, 1997, p. 98).

Similar to what many of the participants verbalized in this study, it is common to see enhanced appreciation of family and friends, as well as a visceral desire to give back to others through volunteer work or career choice (Janoff-Bulman & Frantz, 1997). Alyssa, Amber, Emma, and Michael all articulated ways their choice in careers was driven by an innate desire to give back to others. Lastly, what was initially perceived as a negative event becomes reshaped into something with value in learning more about the self and the world, where the paradigm shifts from suffering to purpose (Janoff-Bulman & Frantz, 1997). However, reaching the destination of finding value and meaning in the self and life is typically preceded by challenging one's self-worth, frequently typified in self-blame or survivors guilt (Janoff-Bulman, 1992; Janoff-Bulman & Frantz, 1997), which was articulated by Alyssa, Amber, and Emma at some chronological point in their story; though some still appear to be struggling with sustained guilt

and blame many years later. These narratives provide compelling implications for the necessity to intervene and provide resources/support that will be discussed below.

Implications for Social Work

The following section will address substantive, theoretical/conceptual, and applied implications. The applied implications will specifically address the third and final research question, "*What are the implications for program/service development and/or enhancement elucidated by identified adults whose sibling experienced a burn injury?*"

Substantive

Literature regarding burn injury trauma has primarily been limited to the experience and impact of the person who sustained the physical burn injury. Although research exploring the systemic impact of a burn injury on the family/caregivers has expanded, there remains room for significant growth and development. Specifically, uninjured siblings are underrepresented in literature with regard to their unique location and perspective in the experience. The significance of sibling relationships is well documented. Therefore, this study provided the first research in over 10 years with a purely qualitative focus that engaged adults through a retrospective method and allowed a more integrated perspective of the experience while also illuminating implications on their identity. The initial three studies utilized minors, with two also engaging parents as proxies. Though there is clear value in future research that re-engages children who are actively developing in childhood with a sibling who experienced a burn injury, the adults were able to provide a more holistic perspective on the experience, as well as contribute more developmentally advanced insights. Furthermore, through the inherent recognition of the uninjured siblings' value and importance, participants in this study suggested they felt

empowered by their involvement, in addition to stimulating advocacy for advances in knowledge, as well as program/service development and/or enhancement.

Theoretical/Conceptual

Theory and conceptual frameworks specific to the experience and impact of a burn injury to uninjured siblings are in their infancy. At this time, with minimal research, it remains ambivalent whether implications on the uninjured siblings' personal development are positive, negative, or both; furthermore, it is important to have greater understanding around the possible influence of uninjured siblings' location within the family, their age at the time of injury, their presence/absence during the injury, the potential impact of burn etiology, family communication styles, and family/individual resource acquisition. However, Burke's (2004, 2010) concept of "disability by association" provided a meaningful framework to understand participants experience in this study and lends itself to further consideration of potential ways to expand conceptually within burn trauma. Specifically, it would be worthwhile to further explore uninjured siblings' perspectives on social exclusion within the context of interventions and/or opportunities (i.e. burn camp) extended to their injured siblings, in addition to what Burke (2004, 2010) posited with regard to their frequent potential for exclusion from peer groups and school. Lastly, though the concept of emotional embargo was only explicitly stated by one participant, the participant's experience appeared to have profound and lasting implications that warrant further theoretical consideration.

Though beyond the scope of this study but related to Burke's (2004, 2010) framework, a deeper understanding of the burn survivor construct warrants additional examination as well. If research can continue to support how uninjured siblings fit within Burke's (2004, 2010) framework of "disability by association" or, what I posited as potentially "burned by

association" or "burned by (dis)association," there will be stronger evidence to argue for expanded inclusion, identity, and resource acquisition within the burn community. However, with the construct of burn survivor still murky within the burn community it remains unclear where research falls within the context of family and siblings. Moreover, the 2016 State of Science meeting specifically detailed:

> [R]esearch priorities of the burn survivor community include 1) conducting survivor-informed research, 2) testing existing interventions, 3) identifying long-term health needs, 4) furthering understanding of the impact of peer support on recovery, 5) measuring prevalence of long-term chronic scar and wound conditions, and 6) establishing long-term rehabilitation services across the life span. (Acton et al., 2017, p. e591)

Without a distinction for how the family and siblings are considered within the burn community, it remains to be seen how the above agenda will prove impactful for this population.

Policy/Applied

Although each contribution is significant in its own right, as a social work practitioner operating directly in the burn community and witnessing firsthand the impact of a burn injury on the entire family system, I am probably the most enthusiastic regarding the applied influence of this study. As previously mentioned, the programs and services within the burn community have traditionally focused on the person with the physical injury. It has just been since 2010 (S. Bruinsma, personal communication, December 15, 2015) that the Phoenix Society for Burn Survivors implemented their annual UBelong program where they "welcome young burn survivors, their siblings and parents, or children of burn survivors to a unique four-day experience." Reviewing the 2016-2017 Federation of Burn Foundations membership directory

provides little clarity about what programs and services are being provided with great specificity in terms of the injured individual, family, and/or siblings. Though, from my professional engagement in the burn community for almost 20 years, I am aware of three organizations that offer specific family programming and one that allows the inclusion of uninjured siblings at the summer burn camp. Needless to say, there remains substantial room for program development and/or enhancement within the scope of the burn community to place greater emphasis on uninjured siblings and the family. Findings from this study suggest that when planning for programs to address the needs of uninjured siblings and families, specific attention is warranted within the context of communication, trauma, and ways to reduce social isolation. Social work is well positioned to make a contribution as a field engaged in work with individuals, families, groups, and communities.

In looking towards the future for possible programs/services there were several suggestions specifically elucidated by the uninjured siblings in this study. Generally speaking, participants advocated for ways to meet other uninjured siblings who shared their experience to engage in peer support. They also articulated a desire to consider formal support sessions that at times could include both injured and uninjured siblings for a cross experience exchange, but then also encouraged creating space for each sibling group (i.e. injured and uninjured) to have their separate support session. Uninjured siblings noted that it may be easier to share specific feelings and emotions in the absence of the injured sibling since they may likely be discussing them and/or the details of the burn injury circumstance. Several of the participants articulated a desire to attend the summer camp program with their siblings if they had been offered the opportunity. This was deemed an activity that would be fun, but more importantly allow them to meet others and develop peer support in the same way their injured siblings experienced it over the years, as

well as develop their own sense of community. In other words, according to Alyssa finding "that one person to have a common ground of understanding." Alyssa was finally able to attend a weekend program that recently included uninjured siblings and acknowledged, "I had a chance to talk about it [the burn trauma] and find out feelings I've actually had about it." The years she was void of opportunities for inclusion in the burn camp program her injured sister attended positioned her on an "island" where she endured an emotional embargo and healing from the traumatic experience was perceived as intangible. Therefore, strong consideration for the inclusion of uninjured siblings at burn camp is warranted. Additionally, programs could be added, such as a long weekend, that include both the injured and uninjured siblings, though it may be a budgetary concern for nonprofits to run multiple programs. Again, the main focus should be to facilitate peer support and create space to assist uninjured siblings normalize their experience, which could likely be considered via programs many organizations are already actively running. Additionally, this a suitable fit for social work professionals from both an advocacy standpoint, as well as program design and implementation.

Uninjured siblings also verbalized family programs or activities were important to consider. These programs or activities provide opportunities to build in components to foster more direct and honest dialogue, thereby minimizing the challenging communication many participants articulated that further compounded the complex dynamics of their situation. Uninjured siblings also felt it was important to ensure their needs and feelings were authentically acknowledged. Participants did not express the expectation for things to be "fixed," but rather articulated a desire to be heard. Though many of these components could be addressed via family programs, a final suggestion made by uninjured siblings in this study was increased access to outside counseling, again within the realm of social work practice. Some of the family and

sibling interventions suggested could ideally begin in the acute hospital setting—since at that time the physical needs/demands of the individual with the burn injury are being met by the medical staff—and endure beyond discharge with increased consideration for each family member as an individual, but also an integral part of the system.

Burke's (2007) book *Social work and disadvantage: Addressing the roots of stigma through association* advocates for the use of the term disadvantage as inclusive—economic, social, and developmental—and defines it as "a factor that permeates the experience of many people who, perhaps not through choice, are vulnerable or stigmatised [*sic*], or are in other ways incapacitated in their dealings with situations and experience of everyday life" (p. 11). Furthermore, disability discussed within his framework of "disability by association" is just one area of disadvantage. Therefore, within the context of social work's commitment to our six core values (NASW, 2017)—service, social justice, dignity and worth of a person, integrity, and competence—we must remain mindful that individual's experiences are not diminished to one area of disadvantage, but instead are likely compounded by other areas including race, socioeconomic status, gender identity, age, and sexual orientation. Therefore, social workers are challenged to utilize their positions in interprofessional settings to educate and advocate that the patient is the entire family—not just the one whose name is on the medical chart—and remain vigilant to other competing forces of disadvantage.

Research often considers how supporting the family will improve upon the well-being of the burn patient (Bond, Gourlay, Desjardins, Bodson-Clermont, & Boucher, 2017). However, the families are often looked to as support for the individuals with the physical injury, without recognizing their own unique needs. Therefore, through the lens of social work's inclusive approach, I encourage shifting the perspective to consider each individual's well-being as worthy

of increased consideration autonomously, with their own unique experiences that would benefit from both independent and inclusive programs and services. Failure to acknowledge and intervene will continue to facilitate missed opportunities and promote potentially life long interpersonal and intrapersonal challenges.

In closing, social work remains a value to interprofessional practice, including the burn team (Abrams & Lloyd, 2019). Interestingly, a recent survey of social workers in burn centers around the country suggested that burn trauma should be an included area of consideration within social work curriculum (Abrams & Lloyd, 2019). Across various levels of social work practice—micro, mezzo, and macro—there are multiple ways to pursue greater engagement in burn trauma within social work education that should be considered. For example, schools of social work could seek out hospital settings (i.e. burn centers) for field placements with medical social workers. Additionally, social workers may be managing programs and services within burn foundations that could provide a field placement. Lastly, there are a number of organizations that run burn camps, which offer an area replete for both social work for practice and research (Dillard, Kolomer, & Hanavan, 2019).

Recommendations for Future Research

The purpose of this study was to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. The adults in the study provided meaningful insights into their experience, yet it is also important to revisit research that includes a sample of children who are actively engaged in developing with their injured sibling. Siblings who are minors reflecting on their current experience has the potential to highlight their immediate needs similar to a study that explicitly explored the needs of adolescent siblings of children and youth with cancer (Tasker & Stonebridge, 2016). It would

then be worthwhile to consider the development and utilization of an instrument similar to the

Sibling Cancer Needs Instrument, which is the first measure to assess the unmet psychosocial

needs of children who siblings are diagnosed with cancer and has implications in clinical settings

to assist in prioritizing interventions for the siblings (McDonald, Patterson, White, Butow, &

Bell, 2015; P. Patterson et al., 2014; P. Patterson, Millar, & Visser, 2011).

    Other areas of consideration regarding the experience of uninjured siblings is how being

born after the sibling endured their burn injury impacts their experience. The etiology of the

injury may also provide additional insights, since two of the participants in this study

experienced a house fire that destroyed their entire home, and thus appeared to endure

heightened grief and loss. Additionally, none of the siblings in this study experienced the

compounded loss of a parent or sibling dying in the burn trauma incident, which would provide

additional areas of understanding in the burn injury experience. Though there were noted

challenges to recruiting uninjured siblings in both Conroy's (2008) study as well as this one,

which may remain the case until services are expanded in the burn community, continuing to

involve uninjured siblings to further inform their needs and experiences remains vital as an area

of research is in its infancy.

    Furthermore, this study specifically looked at the experience of uninjured siblings. Future

research should also consider the impact particular to other roles in a family, such as mothers,

fathers, spouses/partners, and children whose parents experience a burn injury. All of these

studies, as well as additional sibling inquires, could consider the use of varied methodologies

such as dyadic interviews (Morgan, Ataie, Carder, & Hoffman, 2013), as well as a multi-family

member interview study (Reczek, 2014) to enhance understanding the phenomena from more

than one perspective. Lastly, there would be utility in advancing research nationally to assess

what programs/services are being offered by organizations/foundations since this is not clearly outlined. This knowledge can then inform areas to engage program evaluation, which to date appears relatively untapped, particularly as it relates to burn camp, family programs, and young adult retreats.

Conclusions

Sibling relationships are some of the most abiding with countless implications within the context of adjustment and development for the unique dynamic (Dunn, 2000). For uninjured siblings in this study, the narratives articulated numerous ways they experienced their sibling's burn injury as part of their own story. Some endured or continue to sustain trauma in solitude. However, reflecting on their stories allowed them an opportunity to articulate making meaning and understanding more about who they are now or what they learned, as well as innumerable ways their needs were either minimized or unacknowledged. Their experiences of isolation and exclusion did not always appear intentional; yet, their stories highlight opportunities that were lost to provide additional support and resources. Two of the participants grew up during a time when their injured sibling's options of support were minimal, much less consideration for the family. Still, five of the siblings did grow up in an era where aftercare and reintegration were progressing; however, it appeared to focus on the individual with the physical injury. Though the burn community continues to evolve with increased consideration for the family, these seven compelling narratives of uninjured siblings facilitated the closest examination of detailed accounts to date in the literature. Alyssa's own words poignantly convey the overall take away, "We may not have got burned, but we got burned." It is imperative we do not wait another 10 to 20 years to advance progress for uninjured siblings. The time is now.

Chapter Summary

The final chapter provided discussion, implications, recommendations and conclusions for this narrative inquiry. The purpose of this study was to understand the experience of growing up with a sibling who experienced a burn injury in childhood, with attention to how their identity was shaped. Findings were reported as individual stories using pseudonyms for each participant, along with brief artifact descriptions and images (if provided), a metastory, and five overarching themes that included: 1) separation and alternative caregiving, 2) altered interactions and ambivalent roles, 3) (r)evolving emotional pain, 4) communication concerns, and 5) identity through autobiographical reasoning. Based on analysis of the data three broad conclusions were drawn: 1) uninjured siblings have their own unique narratives that have failed to be acknowledged in both research and practice, though all articulated identity clarity and meaning-making in their reflections; 2) many of their experiences warrant consideration as a primary trauma; and 3) there is a critical need to expand attention—specifically as it relates to inclusion, identity, and resource acquisition—within the burn community.

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APPENDICES

Appendix A
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Permission to Reproduce Figure—Oxford University Press

M Gmail   **Dana Dillard** ███████████

Case #00744852 - Copyright Request [ref:_00D30oeGz._5000c1nQVUI:ref]

Dana Dillard ██████████████   Thu, Apr 11, 2019 at 9:47 AM
To: journals.permissions@oup.com

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I would like to request permission to use a figure in the British Journal of Social Work. I attempted yesterday to go in via Rightslink, but was taken to a screen (see below) that said "Contact Oxford University Press." At this point, I called and spoke with a customer service agent there who advised me to go through PLSClear request. I created an account and completed the request, which was subsequently denied, with instructions to go through Rightslink. I also emailed Rightslink customer service and they provided the below response that they were unable to access permission via there service. Therefore, I find myself writing to you directly today in the hopes you can assist. The information I am requesting permission to use is listed below.

Journal: British Journal of Social Work
Article: Brothers and Sisters of Disabled Children: The Experience of Disability by Association
Author: Peter Burke
Year: 2010
Volume: 40
Page: 1685
Item: Figure 1. Disability by Association: interactive effects (revised from Burke, 2004, p. 26)
Intended reuse purpose: Dissertation entitled "YOU'RE PROBABLY THE FIRST PERSON THAT'S ASKED ME": RETROSPECTIVE NARRATIVES OF ADULTS WHOSE SIBLING EXPERIENCED A BURN INJURY

Respectfully,
Dana Dillard
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Dana Dillard ████████████

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To: Dana Dillard ████████████

DefRef

Dear Dana Dillard,

RE. Fig 1. Peter Burke. Brothers and Sisters of Disabled Children: The Experience of Disability by Association. *The British Journal of Social Work* (2010) 40 (6): 1681-1699, doi: 10.1093/bjsw/bcp088

Thank you for your request. Upon review I can confirm the requested figure has been revised from an original source.

As publishers of the above article we have no objection to you using this material. However, it is essential that you clear permission with the original source:

Burke P. (2004) *Brothers and Sisters of Disabled Children*. Jessica Kingsley Publishers. London.

You will also need to acknowledge both sources; i.e. our title plus the original source of the material.

Many thanks for your time.

Kind regards,

Katie

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Appendix C
Permission to Use Photos—Phoenix Society for Burn Survivors

From: Sara Bruinsma
To: Dana Dillard
Subject: RE: Georgia Firefighter Burn Foundation request to use PS photos
Date: Thursday, April 13, 2017 5:23:26 PM

Hi Dana,

Yes, please feel free to use the photos that you attached to your request email. Also, I was having trouble locating the two portrait shots, but I just found them in our archive and watermarked them. ☺

Sara Bruinsma
Phoenix Society for Burn Survivors
1835 RW Berends Dr SW
Grand Rapids, MI 49519-4955

www.phoenix-society.org

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From: Dana Dillard
Sent: Thursday, April 13, 2017 5:12 PM
To: Sara Bruinsma
Subject: Re: Georgia Firefighter Burn Foundation request to use PS photos

Thank you so much Sara.

Just to be clear, can I use both the photographs I sent over, as well as the ones you sent me? I didn't see some of the ones I sent you with a water mark on them (e.g. Cindy and James). I just wanted to double check before working on the flyer. I think my attachments are opening weird in the email platform I'm using.

Many thanks again for your prompt assistance! dd

On Apr 13, 2017, at 4:58 PM, Sara Bruinsma   wrote:

Hi Dana,

If you need any additional photographs, please let me know and I will get those to you on Monday.

Permission to reprint Phoenix Society for Burn Survivors® material.

As we understand your request, you would like to reprint Phoenix Society photographs for a research study that you are working on in collaboration with the University of Georgia School of Social Work. The study will focus on the burn injury experience from the perspective of the sibling who did not sustain the burn injury.

Having reviewed your request, we are happy to grant Georgia Firefighters Burn Foundation and the University of Georgia School of Social Work the permission you seek to reproduce the attached photographic material. Any specific request for additional materials or photos can be made to ███████████████ .

The following credit statement should appear at the beginning or end of the reproduced materials:

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Sincerely,

Sara Bruinsma
Phoenix Society for Burn Survivors
1835 RW Berends Dr SW
Grand Rapids, MI 49519-4955
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From: Dana Dillard ███████████████████
Sent: Thursday, April 13, 2017 1:05 PM
To: Sara Bruinsma ██████████████████
Subject: RE: Georgia Firefighter Burn Foundation request to use PS photos

Thanks so much Sara!

Dana Dillard MSW, LCSW

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From: Sara Bruinsma ███████████████████
Sent: Thursday, April 13, 2017 12:04 PM
To: Dana Dillard ███████████
Subject: RE: Georgia Firefighter Burn Foundation request to use PS photos

Thanks, Dana! I will prepare our permission to use form and watermark some group shots for you. I can get those to you this afternoon. J

Sara Bruinsma
Phoenix Society for Burn Survivors
1835 RW Berends Dr SW
Grand Rapids, MI 49519-4955
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From: Dana Dillard ██████████████
Sent: Wednesday, April 12, 2017 7:50 PM
To: Sara Bruinsma █████████████████
Subject: Re: Georgia Firefighter Burn Foundation request to use PS photos

Hi Sarah.

Thank you so much for getting back to me today!

I am working on a research study with the University of Georgia School of Social Work looking at the burn injury experience from the perspective of the sibling who did not sustain the burn injury. The working title is *Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury*. The hope is to provide insight into their unique perspective to better inform our understanding, as well as program development/enhancement. I am currently working on the IRB application, which I need to submit by next Tuesday. I'm putting together a flyer to recruit participants, which I also need to include in my IRB application, and thought of you all and the great pictures you capture at WBC. Since I'm looking for present day adults, I really wanted to use images of adults and it would be nice if they were group shots demonstrating diversity. I'm not sure if I'll just use one or a small collage of pictures. I haven't gotten into the design phase yet! However, I've attached a few photos I pulled from your FB page as examples of ones I could use, but if you have other ideas I'm open. I really like the picture of James and Cindy Rutter—probably biased because they are friends. But any of those candid group shots like that are fantastic! I'll see Cindy in a few weeks when she's in Atlanta to co-faciliate a retreat with me and I'm sure she'll get a kick if she's used in the flyer. I just need to have something to work with over the weekend so I can get it fine tuned before submission next week. I'm happy to credit the Phoenix Society on the flyer.

Let me know if you need additional information from me. Again, thank you in advance for your time and consideration.

Kind regards,
Dana Dillard MSW, LCSW
████████████
████████████
████████████
████████████
████████

<image006.jpg><image012.jpg><image013.jpg><image014.jpg><image015.jpg><image016.jpg>

> On Apr 12, 2017, at 6:29 PM, Sara Bruinsma ████████████ wrote:
>
> Hi Dana,
>
> Thank you for reaching out to us! I would be happy to assist you with your request. I have just a few questions before moving forward, would you be able to give me a little more background info the project and do you have a particular photo that you would like to use?

Thanks!

Sara Bruinsma
Phoenix Society for Burn Survivors
1835 RW Berends Dr SW
Grand Rapids, MI 49519-4955
████████████████
███████████
███████████████████

www.phoenix-society.org

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On Apr 12, 2017, at 1:55 PM, Andrea Marz ████████████ ███████ wrote:

> Dana Dillard from GFBF called regarding a research flyer she is submitting for a grant in collaboration with the University of GA. She asked if she could use one of our group photos featuring adults. She is happy to use the PS logo on the photo and/or note the photo credit. Would someone be able to follow up with her regarding this request? Her email is ██████████ and her phone is ███████████ ██.
>
> Please let me know.
>
> Thank you,
>
> Andrea Marz
> Executive Assistant
> Phoenix Society for Burn Survivors
> 1835 RW Berends Dr SW
> Grand Rapids, MI 49519
> ██████████████████
> ██████████████
> www.phoenix-society.org
> www.facebook.com/PhoenixSocietyforBurnSurvivors

Appendix D
Recruiting Poster

Photograph reprinted with permission from Phoenix Society for Burn Survivors®. The Phoenix Society, Inc., Grand Rapids, MI. www.phoenix-society.org. All rights reserved.

Appendix E
Recruiting Social Media Post

Participants Wanted

Are you or someone you know the sibling of an individual who experienced a burn injury in childhood and also 19 years of age or older?

If so, please contact Dana Dillard at (404) 320-6223 or via email at ddillard@gfbf.org to learn more about sharing the experience and determining participation eligibility.

Phoenix Society
for burn survivors

Appendix F
Telephone Recruiting and Eligibility Script

Telephone Eligibility Screening and Consent Script

I am calling today to talk to you about a research study called, *Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury*. My name is Dana Dillard, and I am the Programs Director at the Georgia Firefighters Burn Foundation and also a doctoral candidate at the University of Georgia's School of Social Work.

The purpose of this research study is to understand the experience of a burn injury for adults who grew up the sibling of a child with a burn injury. We hope that the study will provide insight into the unique perspective and needs of siblings. The Georgia Firefighters Burn Foundation (GFBF) remains committed to the development/enhancement of their programs/services and this research will help them consider further programming, as well as increase general understanding about what support siblings currently or previously used. Findings from this research will be shared with the GFBF to support program planning, which includes increased consideration of the family system. Your consent will allow the researchers to use the information/data that is collected through your participation in interviews to be included in their research. Do you think you might be interested in participating in this study?

{If No}:   Thank you very much for your time today.

{If Yes}:   Before enrolling people in this study, we need to ask you some questions to determine if you are eligible. What I would like to do now is to ask you a series of questions that should only take about 20 minutes of your time. (If they do not have the time, arrangements will be made for follow up.)

There is a possibility that some of these questions may seem personal and make you uncomfortable or distressed; if so, please let me know. You don't have to answer those questions if you do not want to.

All information that I receive from you during this phone interview, including your name and any other information that can possibly identify you will be strictly confidential. Remember, your participation in this phone interview is voluntary and you can refuse to answer any question, or stop this phone interview at any time without penalty or loss of benefits to which you are otherwise entitled.

Do I have your permission to ask you these questions?

{If No}:   Thank you very much for your time today.

{If Yes}:   Proceed with questions below:
1. First, are you 19 years of age or older?
2. Are you proficient in spoken English?

3. Do you have a sibling through family membership—broadly defined as sharing a connection through biology, marriage, adoption or long-term commitment—who sustained a burn injury that resulted in either inpatient or outpatient hospital treatment settings?
4. Was the injury related to abuse and/or neglect?
5. Were you and that sibling both minors (under the age of 18) for at least two years following the burn injury?
6. Did you and that sibling live together at the time of the burn injury, regardless of family membership?
7. Do you have any developmental or cognitive diagnosis, which would prevent your ability to participate in the study?

{If Eligible}: Based on the answers above you meet the criteria to participate in the study. At this time, I will tell you additional details of the study.

- If you agree to participate, please note you have the right to change your mind before, or during the study, even after agreeing.
- If you agree to participate, you will be asked to take part in an interview lasting between 1 to 1 ½ hours at time and location to be determined. While arranging the interview, you will also be asked to bring an artifact to the interview (e.g. letter, journal entry, photograph, etc.) you feel symbolizes your sibling relationship, either before, during or after the burn injury. This will be used to help guide our conversation, as well as an additional source of data. We will take a photograph of the artifact, which will also be analyzed/interpreted and potentially represented in further print materials for publication/presentation. If you choose to bring artifacts with identifying information, you have the option to have identifying elements, such as your face/name/etc., blurred or blocked out when used in print materials for publication/presentation. These artifacts are requested and strongly encouraged, but not required, for participation in the study. You will also be provided a brief written questionnaire to complete that asks information related to the burn injury incident, as well as your consent for the use of artifact images if provided. If you need assistance with reading or writing, the researcher is prepared to help. After you complete the questionnaire the interview will begin. Examples of interview questions include: 1) Tell me about the event/circumstances that resulted in the burn injury; 2) Describe what the experience of the incident was like for you; 3) How would you describe your relationship with your sibling and/or family before the burn injury?; 4) How would you describe your relationship with your sibling and/or family after the burn injury?; 5) How would you describe your relationship with your sibling and/or family now?; 6) What kind of communication do you and your sibling/family have regarding the injury now? 7) What do you wish other people understood about burn injuries? 8) What support was offered to you at the time of the incident? What was helpful? What was not helpful? Discussions will be recorded using iPhones and/or other audio equipment and transcribed. At the end of the interview, you will be reminded of the possible need for follow up to collect additional information or clarify something that was said. If needed, follow up arrangements will be made with you later. Considering the possibility for follow up, your total participant time is approximately three to four hours.
- There is minimal risk associated with this research. Potentially stress might occur due to reflecting upon the experience of the burn injury. Although we have made every effort to

minimize this, you may find some of the questions to be upsetting or stressful. Researchers will caution you that some of the questions may be upsetting at the start of the discussion, but that this risk would be rare. However, if you do become distressed you will be reminded that your participation is voluntary and you have the option to move on to another question, and if necessary withdraw from the study completely without any penalty or loss of benefit. If it becomes needed, researchers will provide referrals to resources. Furthermore, the researcher conducting the interviews has extensive experience working with individuals impacted by burn injuries and is also a licensed clinical social worker.

- You will not get any direct personal benefit from taking part in this study. However, because this research will provide the GFBF with knowledge that may result in new/enhanced programming, potential benefits extend to the existing larger burn community. Through the sharing of your own story facilitated by this research opportunity, it is anticipated the needs of siblings of children with burn injuries will be highlighted.

- You will not receive any payment or reward for taking part in this study.

- Audio files and transcripts will be stored in a password protected cloud drive (e.g. Dropbox or Google Drive), as well as password protected computers. Pseudonyms will be assigned to each participant and employed in the transcription. Once the audio files are fully transcribed and reviewed against the transcription for accuracy they will be deleted. If you provide an artifact, researchers will take a photograph of the image, which will also be stored in a password protected cloud drive (e.g. Dropbox or Google Drive), as well as password protected computers. These images will also be maintained until completion of the analysis and written manuscript, at which time all information will be deleted.

- You will not be directly identified in any published or presented materials, unless you choose to provide an artifact with identifying information. However, as previously stated, you have the option to have identifying elements, such as your face/name/etc., blurred or blocked out when used in print materials for publication/presentation. Again, these artifacts are requested and strongly encouraged, but not required, for participation in the study. All information will be confidential, and pseudonyms will be used in the transcription and any other published materials. We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information or what that information is. Although all data will be deidentified (i.e. use of pseudonyms) prior to being analyzed for research purposes, your name and contact information will be kept separate, so that researchers are able to follow up if needed for additional data collection and/or clarification after the initial interview. Since it may become necessary to follow up with participants after the initial interview, this information will be kept until completion of data analysis and written results/discussion. Upon completion of the final analysis and written manuscript all information will be deleted. It is anticipated a maximum duration of two years post data collection. That said, it is possible researchers will be able to directly identify participants during analysis from a combination of indirect identifiers since the interviews will likely take place face to face, as well as involve in-depth inquiry into a unique incident.

- There are some circumstances in which we may have to show your information to other people. We may be required to show information that identifies you to people who need

to be sure that we have done the research correctly, such as the UGA Institutional Review Board. Moreover, the law may require us to show your information in court, or to tell authorities if there are concerns of you being a danger to yourself or others.

If you would like to participate in the study we can arrange a time for the interview. If the interview is not done in person, I will mail the informed consent and brief questionnaire along with a self-addressed stamped envelope for you to return the documents.
After learning more details about the study, do you have any questions at this time? If you have any questions later, please feel free to call me at (404) 320-6223 or you can contact the Principal Investigator, Dr. Larry Nackerud at (706) 542-3364 or nackerud@uga.edu.

OR

{If Ineligible}: Unfortunately, based on the answers above you did not meet the criteria to participate in this study. Thank you very much for your time today and interest in the study.

**Appendix G
IRB Approval—Initial**

Phone 706-542-3199

Office of the Vice President for Research
Institutional Review Board

DETERMINATION OF EXEMPTION

April 25, 2017

Dear Larry Nackerud:

On 4/25/2017, the IRB reviewed the following submission:

Type of Review:	Initial Study
Review Category:	Exempt 2
Title of Study:	Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury
Investigator:	Larry Nackerud
Student Co-Investigator:	Dana Dillard
IRB ID:	STUDY00004758
Funding:	None
Grant ID:	None
Documents Reviewed:	Recruitment Material, Consent Documents, Data Collection Instruments, Site Authorization

The IRB approved the protocol on 4/25/2017 to 4/24/2022.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103).

Sincerely,

Dr. Gerald E. Crites, MD, MEd
University of Georgia
Institutional Review Board Chairperson

310 East Campus Rd, Tucker Hall Room 212 ◆ Athens, Georgia 30602
An Equal Opportunity/Affirmative Action Institution

Appendix H
IRB Approval—Modification

The University of Georgia

Phone 706-542-3199

Office of the Vice President for Research
Institutional Review Board

DETERMINATION OF EXEMPTION

April 25, 2017

Dear Larry Nackerud:

On 4/25/2017, the IRB reviewed the following submission:

Type of Review:	Initial Study
Review Category:	Exempt 2
Title of Study:	Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury
Investigator:	Larry Nackerud
Student Co-Investigator:	Dana Dillard
IRB ID:	STUDY00004758
Funding:	None
Grant ID:	None
Documents Reviewed:	Recruitment Material, Consent Documents, Data Collection Instruments, Site Authorization

The IRB approved the protocol on 4/25/2017 to 4/24/2022.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103).

Sincerely,

Dr. Gerald E. Crites, MD, MEd
University of Georgia
Institutional Review Board Chairperson

310 East Campus Rd, Tucker Hall Room 212 ◆ Athens, Georgia 30602
An Equal Opportunity/Affirmative Action Institution

Appendix I
IRB Consent Form

**UNIVERSITY OF GEORGIA
CONSENT FORM**

Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury

Researcher's Statement
We are asking you to take part in a research study. Before you decide if you will participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether you should be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Investigators: **Dr. Larry Nackerud** (Principal Investigator)
School of Social Work UGA (706) 542-3364
Dana R. Dillard
School of Social Work UGA and Georgia Firefighters Burn Foundation
(706) 542-3364 (UGA) or (404) 320-6223 (GFBF) or ddillard@gfbf.org

Purpose of the Study
The purpose of this research study is to understand the experience of a burn injury for adults who grew up the sibling of a child with a burn injury. We hope that the study will provide insight into the unique perspective and needs of siblings. The Georgia Firefighters Burn Foundation (GFBF) remains committed to the development/enhancement of their programs/services and this research will help them consider further programming, as well as increase general understanding about what support siblings currently or previously used. Findings from this research will be shared with the GFBF to support program planning, which includes increased consideration of the family system. Your consent will allow the researchers to use the information/data that is collected through your participation in interviews to be included in their research.

You are being invited to participate based on your relationship to a sibling who experienced a burn injury in childhood. Specifically, you have met the following criteria to be eligible for this study: (1) adults (19 years of age or older) who through family membership—broadly defined as sharing a connection through biology, marriage, adoption or long-term commitment—have a brother or sister who sustained a burn injury that resulted in either inpatient or outpatient hospital treatment settings; (2) siblings must have both been minors (under the age of 18) for at least two years following the burn injury; (3) lived together at the time of the burn injury, regardless of family membership; and (4) are proficient in spoken English; additionally, (5) the

burn injury was not related to abuse and/or neglect and (6) you do not have a developmental or cognitive diagnosis that would impair your ability to participate.

Study Procedures
If you agree to participate, you will be asked to take part in an interview lasting between 1 to 1 ½ hours at time and location to be determined between you and the researcher. While arranging the interview, you will also be asked to bring an artifact to the interview (e.g. letter, journal entry, photograph, etc.) you feel symbolizes your sibling relationship, either before, during or after the burn injury. This will be used to help guide our conversation, as well as an additional source of data. We will take a photograph of the artifact, which will also be analyzed/interpreted and potentially represented in further print materials for publication/presentation. If you choose to bring artifacts with identifying information, you have the option to have identifying elements, such as your face/name/etc., blurred or blocked out when used in print materials for publication/presentation. These artifacts are requested and strongly encouraged, but not required, for participation in the study.
At the start of the interview, the researcher will review information about the study, including information discussed in this informed consent. You will also be provided a brief written questionnaire to complete that asks information related to the burn injury incident, as well as your consent for the use of artifact images if provided. If you need assistance with reading or writing, the researcher is prepared to help. After you complete the questionnaire the interview will begin. Examples of interview questions include: 1) Tell me about the event/circumstances that resulted in the burn injury; 2) Describe what the experience of the incident was like for you; 3) How would you describe your relationship with your sibling and/or family before the burn injury?; 4) How would you describe your relationship with your sibling and/or family after the burn injury?; 5) How would you describe your relationship with your sibling and/or family now?; 6) What kind of communication do you and your sibling/family have regarding the injury now? 7) What do you wish other people understood about burn injuries? 8) What support was offered to you at the time of the incident? What was helpful? What was not helpful? Discussions will be recorded using iPhones and/or other audio equipment and transcribed. At the end of the interview, you will be reminded of the possible need for follow up to collect additional information or clarify something that was said. If needed, follow up arrangements will be made with you later. Considering the possibility for follow up, your total participant time is approximately three to four hours.

Risks and discomforts
There is minimal risk associated with this research. Potentially stress might occur due to reflecting upon the experience of the burn injury. Although we have made every effort to minimize this, you may find some of the questions to be upsetting or stressful. The researcher will caution you that some of the questions may be upsetting at the start of the discussion, but that this risk would be rare. However, if you do become distressed you will be reminded that your participation is voluntary and you have the option to move on to another question, and if necessary withdraw from the study completely without any penalty or loss of benefit. If it becomes needed, you will be provided referrals to resources. Furthermore, the researcher

conducting the interviews has extensive experience working with individuals impacted by burn injuries and is also a licensed clinical social worker.

Benefits

You will not get any direct personal benefit from taking part in this study. However, because this research will provide the GFBF with knowledge that may result in new/enhanced programming, potential benefits extend to the existing larger burn community. Through the sharing of your own story facilitated by this research opportunity, it is anticipated the needs of siblings of children with burn injuries will be highlighted.

Incentives for participation

You will not receive any payment or reward for taking part in this study.

Audio/Video/Visual Recording

To stay attentive to the interview and enhance the accuracy of data collection, the conversation will be recorded using iPhones and/or other audio equipment and transcribed. Audio files and transcripts will be stored in a password protected cloud drive (e.g. Dropbox or Google Drive), as well as password protected computers. Once the audio files are fully transcribed and reviewed against the transcription for accuracy they will be deleted. If you provide an artifact, researchers will take a photograph, which will also be stored in a password protected cloud drive (e.g. Dropbox or Google Drive), as well as password protected computers. These images will also be maintained until completion of the analysis and written manuscript, at which time all information will be deleted.

Privacy/Confidentiality

You will not be directly identified in any published or presented materials, unless you choose to provide an artifact with identifying information. However, as previously stated, you have the option to have identifying elements, such as your face/name/etc., blurred or blocked out when used in print materials for publication/presentation. Again, these artifacts are requested and strongly encouraged, but not required, for participation in the study. All information will be confidential, and pseudonyms will be used in the transcription and any other published materials. We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information or what that information is. Although all data will be deidentified (i.e. use of pseudonyms) prior to being analyzed for research purposes, your name and contact information will be kept separate, so that researchers are able to follow up if needed for additional data collection and/or clarification after the initial interview. Since it may become necessary to follow up with participants after the initial interview, this information will be kept until completion of data analysis and written results/discussion. Upon completion of the final analysis and written manuscript all information will be deleted. It is anticipated a maximum duration of two years post data collection. That said, it is possible researchers will be able to directly identify participants during analysis from a combination of indirect identifiers since the interviews will likely take place face to face, as well as involve in-depth inquiry into a unique incident.

There are some circumstances in which we may have to show your information to other people. We may be required to show information that identifies you to people who need to be sure that we have done the research correctly, such as the UGA Institutional Review Board. Moreover, the law may require us to show your information in court, or to tell authorities if there are concerns you being a danger to yourself or others.

Taking part is voluntary
If you agree to participate it should be because you really want to volunteer. Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled. You can decide not to participate, even after you have consented. Please remember, you have the right to change your mind before, or during the study, even after agreeing. If you decide to stop or withdraw from the study, the information/data collected from or about you up to the point of your withdrawal will be kept as part of the study and may continue to be analyzed. No one on the research team will behave any differently toward you if you choose not to participate in the study.

If you have questions
The principal investigator conducting this study is Dr. Larry Nackerud, professor at the University of Georgia. Dana R. Dillard, a doctoral candidate at the University of Georgia, and also Programs Director at the Georgia Firefighters Burn Foundation, is a co-investigator. Please ask any questions you have now. If you have questions later, you may contact Dr. Nackerud at (706) 542-3364 or Dana at (706) 542-3364, (404) 320-6223, or ddillard@gfbf.org. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form and have had all of your questions answered.

Name of Researcher: _____Date _____

Signature of Researcher: _____

Name of Participant: _____Date _____

Signature of Participant: _____

Please sign both copies, keep one and return one to the researcher.

Appendix J
Interview Guide

Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury

Hi! My name is Dana Dillard and I am the Programs Director at the Georgia Firefighters Burn Foundation (GFBF) and a Social Work doctoral candidate at the University of Georgia. You are being invited to participate in a research study entitled ***Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury***. During my 18 years in the burn community I have observed an emphasis on programs and services for the individual that experienced the physical burn injury. However, it seems likely that the distress extends beyond the individual who experienced the physical injury and impacts the entire family system, especially the sibling relationship. Therefore, I would like to better understand the experience and support needs from your perspective as a sibling. In other words, what is your story growing up the sibling of a child with a burn injury?

The GFBF currently offers two Family Weekend programs a year to provide support to the family system. Additionally, siblings are now able to attend our weeklong summer camp, which prior to 2016 only included the children who sustained the burn injury. The GFBF is excited to grow our programs and understanding of the burn injury experience, which is why we are asking for your input here today. Findings from this research will be shared with GFBF, as well as the burn and research communities at large, to further support and enhance program planning, including increased consideration of the family system. I appreciate you meeting with me today to talk more about your experience.

Before we begin the interview, I would like to remind you that the information you share during the interview will be kept confidential as explained in the consent form. I will not use your name or any other identifying information about you that might allow someone to figure out who you are. Please think of this as a conversation and feel free to ask me any questions as we go along. You have the option to skip questions you do not want to answer and remember you may withdraw your consent and end the interview at any time without penalty or loss of benefits to which you are otherwise entitled. I anticipate the interview will last between 60-90 minutes.

At this point, do you have any questions before we begin?

Transition: I would like to start our conversation by learning more about the specific event/circumstances that resulted in the burn injury of your sibling/brother/sister. I realize this may be difficult for you to discuss so please take your time and share at your comfort level.

RESEARCH QUESTION: What are the experiences, or stories, of adults who grew up the sibling of a child with a burn injury? AND What do the narratives of adult siblings of children with burn injuries reveal about how their identities were shaped? AND How do adult siblings of children with burn injuries organize, narrate, and construct those life experiences?

1. Tell me about the event/circumstances that resulted in the burn injury.

Probing questions if needed: Where did it take place? What was the cause of injury—house fire, boiling water, car accident, fireworks, etc.? What do you remember about the timing or order of events following the incident? What time of day did it happen? What was the weather? What time of year?

2. Describe what the experience of the incident was like for you.
   Probing questions if needed: Tell me what about that particular moment stands out. Where were you when it occurred? How did you learn about the injury? If someone else told you, what do you remember them saying to you? Who else was present? What do you remember about the sights and sounds from the event? How did you respond? What emotions do you remember feeling? What actions do you remember? Who took care of you if you were not with immediate family following the incident? If I followed you through the first days after the injury what experiences would observe? And _____ years/months later, how would you describe your life/routine now? How do you feel about the burn injury?

3. How would you describe your relationship with your sibling and/or family before the burn injury?
   Probing questions if needed: What types of things did you and your sibling and/or family do together? What stands out the most for you doing that period? What kinds of plans or thoughts did you have about your future?

4. How would you describe your relationship with your sibling and/or family after the burn injury?
   Probing questions if needed: What changed? What stayed the same? What stands out the most for you doing that period? How did the burn injury impact plans or thoughts about your future? Can you remember a specific time when you thought about what your life or your routine seemed like before the injury? Why does that moment stand out?

5. How would you describe your relationship with your sibling and/or family now?
   Probing questions if needed: What changed? What stayed the same? What kind of impact do you think the burn injury had in your life looking back?

6. What kind of communication do you and your sibling have regarding the injury now?
   Probing questions if needed: If they do discuss, what is the topic of those conversations? Feelings/emotions? Guilt? Anger? How do the conversations typically start? If they do not discuss, what do you think are the reasons for the lack of conversation? What would you like to see the communication look like? Who do you talk to about the injury?

7. What kind of communication do you and your family have regarding the injury now?
   Probing questions if needed: If they do discuss, what is the topic of those conversations? Feelings/emotions? Guilt? Anger? How do the conversations typically start? If they do not discuss, what do you think are the reasons for the lack of conversation? What would you like to see the communication look like?

Transition: After learning about your story I would like to discuss your thoughts regarding programs and services to gain further insight—both positively and/or negatively. (*These questions will likely be addressed more implicitly; however, they are included if needed*).
RESEARCH QUESTIONS: What are the implications for program/service development and/or enhancement elucidated by siblings of children with burn injuries?

8. Over the years, individuals shared things with me they wished other people understood about burn injuries, such as the permanence of scarring. What do you wish other people understood about burn injuries?
    Probing questions if needed: What is important to know about burn injuries from a physical standpoint? What is important for people to understand from an emotional perspective? What do you think is the most important thing for others to know about burn injuries? Why? What have you learned through this experience?

9. What support was offered to you at the time of the incident? What was helpful? What was not helpful?
    Probing questions if needed: What help do you remember being offered by the medical staff? Family? Friends? Work? Church? Outside organizations? What support do you remember wishing you received? Or wishing you did not receive? What were things people said or did you found comfort in? What were things people said or did that made you upset? How did you feel about receiving support?

10. Right now, the GFBF offers programs such as summer camp, which now includes siblings, two family weekends, and a young adult retreat for 18-25 years old who experienced a burn injury. What other programs could be offered?
    Probing questions if needed: What would you like to see programming look like? If you could wake up tomorrow and have any kind of programs/services available what would you want for other siblings and/or families?

Final thoughts: I realize we have talked about a lot of things, so before we conclude I want to give you the opportunity to share anything else you would like to add or feel may have been missed.

Concluding statement: If you do not have anything else, I would like to thank you for your time and insight. I appreciate your willingness to share your personal story with me. If I have any follow up questions, would it be okay if I contacted you for a brief follow up? **OR** Thank you for bringing up the issue/topic/etc. of _____, which we did not get a chance to discuss at length. I appreciate your willingness to share your personal story with me. If I have any follow up questions, would it be okay if I contacted you for a brief follow up?

Appendix K
Participant Questionnaire/Artifact Consent

Retrospective Narratives of Adults Who Grew up the Sibling of a Child with a Burn Injury Participant Questionnaire	
1. What year did the burn injury happen?	
2. How old were you when your sibling experienced their burn injury?	
3. How old are you now?	
4. Where do you fall in the birth order of your family?	❏First born ❏ Middle child ❏ Youngest child
5. How old was your sibling when they experienced their burn injury?	
6. How old is your sibling now?	
7. About how long was your sibling hospitalized?	
8. If known, what percentage of total surface body area (usually expressed as a percentage) was effected and what type (1st, 2nd, 3rd degree) of burn? For example: *30% 2nd degree burn*	
9. What area(s) were injured?	
10. Who were your primary caregivers (i.e. who took care of you) before the burn injury?	
11. Who were your primary caregivers (i.e. who took care of you) after the burn injury?	
12. What is your identified gender?	
13. What is your identified race/ethnicity?	
14. What is your religious/spiritual affiliation?	
15. What is your current marital status?	
16. What is your highest level of education/training?	
17. What is your current occupation?	

Retrospective Narratives of Adults Who Grew up the
Sibling of a Child with a Burn Injury
Artifact Consent

You were asked to bring an artifact to the interview (e.g. letter, journal entry, photograph, etc.) you feel symbolizes your sibling relationship, either before, during or after the burn injury. This will be used to help guide our conversation, as well as an additional source of data. We will take a photograph of the artifact, which will also be analyzed/interpreted and potentially represented in further print materials for publication/presentation. If you choose to bring artifacts with identifying information, you have the option to have identifying elements, such as your face/name/etc., blurred or blocked out when used in print materials for publication/presentation. These artifacts are requested and strongly encouraged, but not required, for participation in the study.

**Please note: This will be filed with your informed consent.

Place a ☒ or ☑ in ONE of the boxes below AND initial in the box to the right:

☐ I am providing an artifact to be photographed by the researchers and I consent to the image of my artifact being used in print materials for publication/presentation as is.	
☐ I am providing an artifact to be photographed by the researchers I and consent to the image of my artifact being used with the following conditions:	
☐ I am NOT providing an artifact.	

_____

Printed Name   Date

_____

Signature

_____

Table 1

Participant Demographic Profile

	Age at time of study [a]	Age when sibling injured [a]	Gender	Position in birth order	Ethnicity	Religious affiliation	Marital status	Highest level of education	Current occupation
Alyssa	20	3	Female	Youngest	White	Baptist/ Christian	Single	High school	Assistant Store Manager/911 Dispatch Officer
Amber	32	13	Female	First Born	White	No response	In relationship[b]	College	Manager/Trainer
Isaac	24	3	Male	Youngest	White	Atheist	In relationship	High school	Fork Lift Driver
Oliver	53	2 years & 9 months	Male	First Born	White	Spiritual	Single	Trade school	Cosmetologist
Ursala	57	10	Female	Middle	White	Catholic	Married	College	Licensed Personal Banker
Emma	21	5	Female	First Born	White	No response	Married	Some college	Baker
Michael	25	0	Male	Youngest	White	No response	Single	College	Program Assistant in College of Education/Assistant Basketball Coach

Note. All names are pseudonyms and listed in the order of their interview.
[a]=Years unless otherwise noted.
[b]=Response left blank on demographic sheet. During interview she specified being in a relationship. During member check she stated she was now single.

Table 2

Injured Sibling Information

	Sibling(s) name	Etiology	Age of sibling(s) when injured[a]	Sibling(s) Gender	Weeks Hospitalized	TBSA	Degree	Areas of body burned[b]
Alyssa	Tiffany	Ignited Gas Can/House Fire	3	Female	12	75%	3rd	A, T, L, FT, HA
Amber	Cody	House Fire	5	Male	24	85%	3rd	EB
Isaac	Noah	Scald	6	Male	Unknown	Unknown	Unknown	N, B
Oliver	Scott	Scald	8 months	Male	8	65%	2nd & 3rd	HE, F, T, Left A, L, FT
Ursala	Ruth/Rose	Campfire	7/12	Female/ Female	24/6	65%/30%	Unknown/ Unknown	F, L, T/L
Emma	Isabella	Contact with Hot Ash	1.5	Female	6	Unknown	3rd	L, Right HA
Michael	Irene	Scald	2	Female	5	10%	3rd	HA

Note. All names are pseudonyms and listed in the order of their interview; TBSA=total body surface area
[a]=Years unless otherwise noted.
[b]A=arms, B=back, C=chest, EB= entire body, F=face, FT=feet, HA=hands, HE=head, L=legs, N=Neck, T=torso

Table 3

Themes and Descriptions

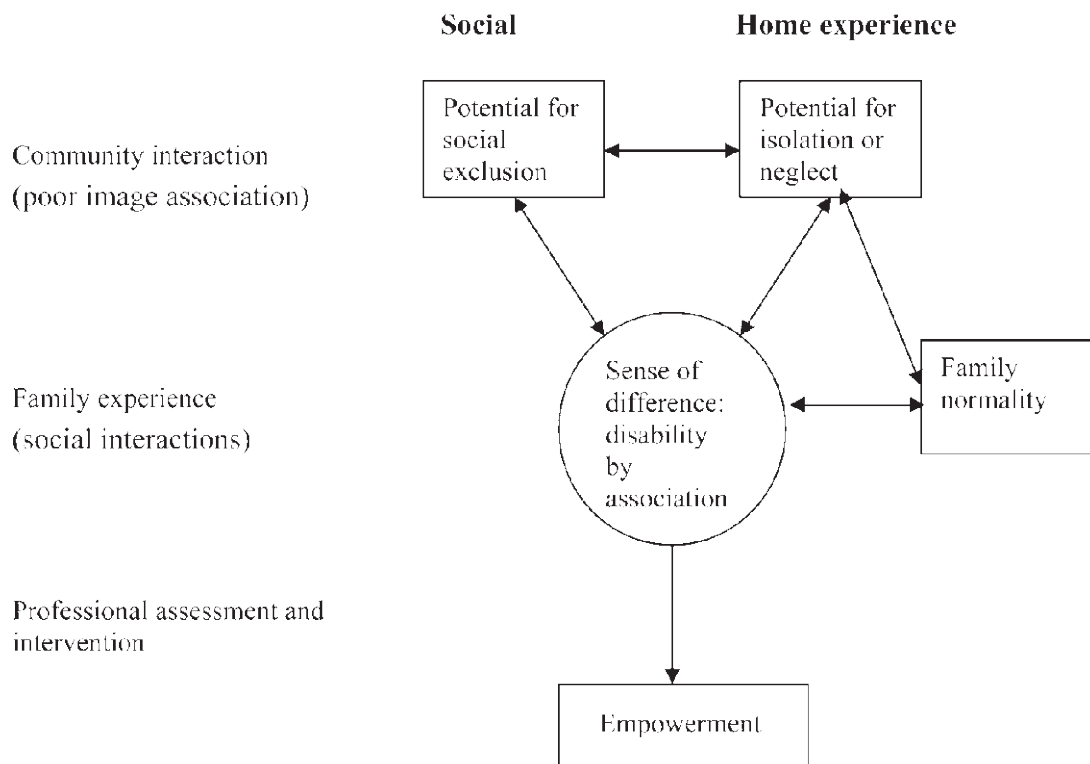| Theme	Description
Separation and Alternative Caregiving	Burn injuries commonly require extended stays at a hospital/burn center for both acute and ongoing treatments. Consequently, uninjured siblings were often separated from their parents and injured siblings during these times and cared for by other people.
Altered Interactions and Ambivalent Roles	Burn injuries are a physical trauma to the body that can cause temporary or prolonged cosmetic changes, as well as renegotiated mobility and/or activity levels. This transformation generates nuanced adaptations to how others engage (or disengage) with both the injured individual and their family. Changes in family functioning are also possible. Therefore, uninjured siblings experienced new interactions and roles (e.g. protector/advocate or caregiver) in the family and with others.
(R)evolving Emotional Pain	Uninjured siblings experienced difficult emotions that continued to evolve after the acute incident of a burn injury, as well as during hospitalization, aftercare, and community/family reintegration.
Communication Concerns	Uninjured siblings experienced communication that was oftentimes non-existent or indirect after the acute incident of a burn injury, as well during hospitalization, aftercare, and community/family reintegration.
Identity through Autobiographical Reasoning	Uninjured siblings articulated the promotion of self-growth by connecting past events to the current self through advancing interpretative or reflexive processes and sharing their experience/story.

Social   **Home experience**

Community interaction
(poor image association)

Family experience
(social interactions)

Professional assessment and
intervention

| Potential for social exclusion | ⟷ | Potential for isolation or neglect |

Sense of difference: disability by association

Family normality

Empowerment

Figure 1. Disability by association: interactive effects (revised from Burke, 2004, p. 26, 2010, p. 1685); permission to use figures by Jessica Kingsley Publishers (Appendix A) and Oxford University Press (Appendix B), respectively

Figure 2. Isaac's artifact
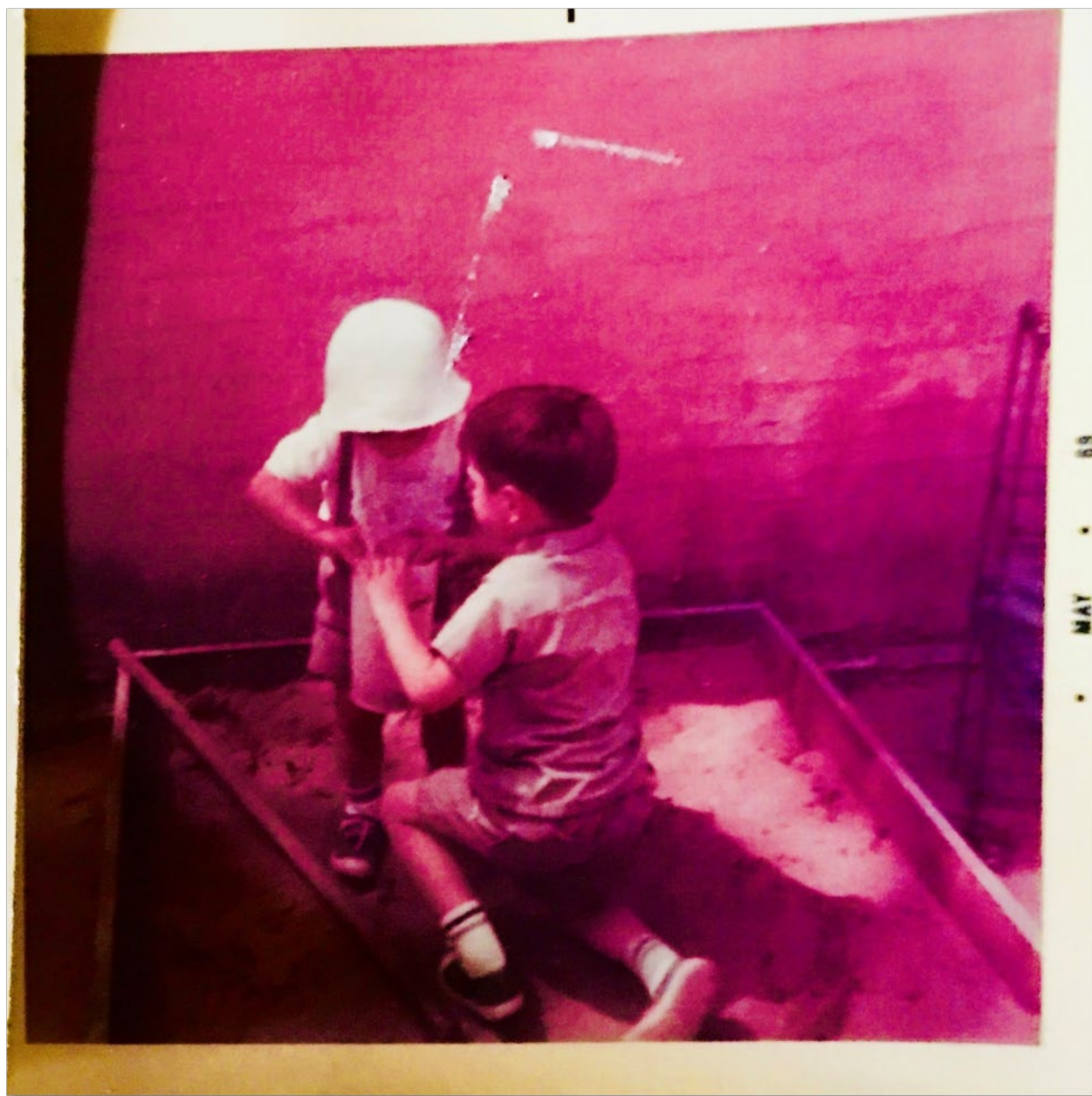
Figure 3. Oliver's Artifact (Scott left; Oliver right)

Figure 4. Oliver's artifact (Scott left; Oliver right)
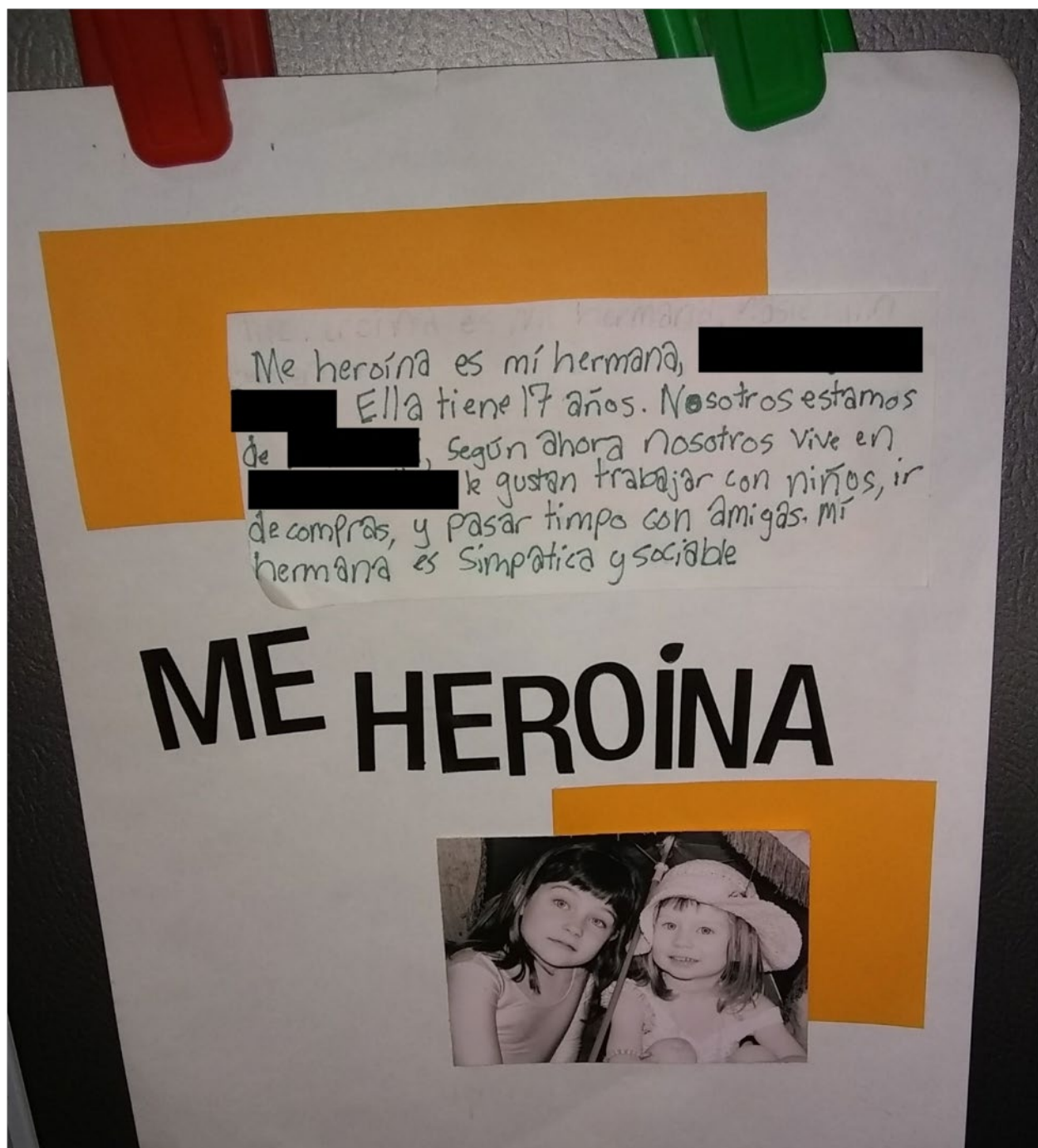
Figure 5. Emma's artifact (Emma left; Isabella right)

Figure 6. Michael's artifact (Michael left; Irene right)

Figure 7. Michael's artifact (Michael left; Irene right)