

STIGMA AND SEXUALITY: HOW BURN SURVIVORS AND  
RELATIONAL PARTNERS MANAGE THEIR EXPERIENCES

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**TABLE OF CONTENTS**

LIST OF TABLES .....	viii
ABSTRACT.....	ix
CHAPTER 1: INTRODUCTION .....	1
Statement of the Problem .....	2
Justification and Focus .....	4
Burn Injuries .....	4
Struggles of Burn Survivors .....	6
Practical Contributions.....	12
Summary .....	13
CHAPTER 2: LITERATURE REVIEW .....	14
Experiencing a Burn Injury – Physical Aspects.....	14
Experiencing Stigma .....	17
Defining and Managing Stigma.....	18
Interpersonal Interactions .....	22
Resilience.....	24
Summary of Stigma and Related Research Question.....	27
Experiencing Sexuality .....	28
Defining Sexuality.....	28

Summary of Sexuality and Related Research Question.....	43
Summary of the Study and Research Questions .....	43
CHAPTER 3: METHODS.....	45
Interpretive Paradigm.....	45
Hermeneutic Phenomenological Methodology.....	46
Researcher’s Standpoint.....	49
Data Collection.....	51
Participants .....	51
Sampling.....	54
Recruitment .....	55
Interviews .....	57
Data Analysis .....	59
Analyzing Stigma Strategy Use.....	60
Analyzing Sexuality .....	62
Validation strategies .....	62
Summary .....	63
CHAPTER 4: RESULTS.....	64
RQ1: Stigma Management.....	64
Survivor Strategy Use.....	65
Partners’ Strategy Use .....	87

Summary of RQ1 .....	92
RQ2: Sexuality .....	93
Sexuality as Feeling Not Sexy.....	94
Sexuality as Fragile .....	99
Sexuality as Being a New Normal.....	103
Sexuality as Not Being Impacted .....	106
Summary of RQ2.....	112
Summary of Results .....	113
CHAPTER 5: DISCUSSION.....	114
Summary of Findings .....	114
RQ1: Stigma .....	114
RQ2: Sexuality .....	120
Theoretical Implications.....	122
Stigma Management Communication .....	122
Sexuality .....	131
Practical Applications .....	134
Strengths.....	137
Contribution to Interpersonal Communication.....	137
Breadth of Participants .....	138
Inclusion of Partners .....	138

Limitations .....	139
Participant Variety .....	139
Unemployment .....	139
Intimate Topic.....	140
Validation Strategies.....	141
Conclusion.....	141
References.....	142
Appendix A.....	153
Appendix B.....	154
Appendix C.....	155
Appendix D.....	156
Appendix E.....	158
VITA.....	160



**LIST OF TABLES**

Table 1	
Profiles of Burn Survivors .....	54
Table 2	
Profiles of Relational Partners .....	55
Table 3	
Survivor Stigma Strategies .....	62
Table 4	
Survivor Stigma Management Patterns .....	67

## ABSTRACT

Burn survivors and their injuries are studied exhaustively while in the context of the hospital; however what happens after they leave and interact with others is under-researched. Despite the expansive amount of research in the areas of stigma communication, sexuality, and burn survivor, scholars have yet to examine the stigma and sexuality experiences of survivors and relational partners. Through hermeneutic phenomenology, this study explores the stigma management and sexuality experiences of both survivors and relational partners. Interviews were conducted with 19 survivors and 8 relational partners across the United States. Results indicated that survivors managed stigma using the following four strategy patterns: Accepters, Situational Adopters, Challengers, and Dissembling Challengers. Relational partners a different pattern to manage stigma. While stigma seemed to be constructed separately by survivors and partners, sexuality was more clearly co-constructed. Sexuality of the survivor was co-constructed as: feeling not sexy, being fragile, being a new normal, and not being impacted. Implications for addition of the interpersonal context to the SMC model, patterns of stigma strategies, and future research are presented.

Keywords: stigma, sexuality, burn survivors, stigma management, interpersonal communication

## CHAPTER 1: INTRODUCTION

Firefighters are heroes who often save the day, but sometimes things go horribly wrong. Such was the case for Duane Wright in 1989 when he was caught in a firestorm. Duane awoke from a medically induced coma in a burn unit to what he calls “a nightmare.” Duane spent seven weeks fighting for his life in the burn unit. “The recovery process was absolute torture,” Duane recalled. It took a year for him to recover his range of motion and return to work. He also struggled due to insecurities about his appearance (Mabie & Caminata, 2011). Other burn survivors, as reported in a study that examined sexual education strategies, have indicated similar concerns with body image:

The biggest impact for me was image. It was how other people would see me. If I look into a mirror I don't see anything beautiful looking about my body I see scars and ugliness ... I automatically assumed that's how the opposite sex or whatever would perceive me as well (Parrot & Esmail, 2010, p. 90).

In a qualitative study focused on sexuality issues of survivors as they came of age, Parrot and Esmail (2010) found that body image can certainly impact how an individual feels as a sexual being. Thus, actual physical limitations of burn survivors may also alter feelings of sexuality and intimacy:

A lot of the times we have limited movement, so therefore some of the sexual positions just are not comfortable. And there is also the loss of feeling depending on how deep the burn is you can have absolutely no feeling, for myself, ... I have no feeling in the breast what so ever (Parrot & Esmail, 2010, p. 90).

Each of these statements gives one a glimpse into the challenges a survivor may face. This initial research invites further research that investigates constructions of sexuality for a wider range of survivors (i.e., more than childhood burn survivors). As the author of the current dissertation, interest in survivor scholarship stems from my own experiences as a burn survivor. Twenty years ago, I was a 17 year-old girl with a body suddenly covered in burn scars. At the time, I was convinced that no one would ever

want to date me. The next several years were very challenging to navigate in terms of relationships. My sense of self was no longer steady as I had to figure out how to incorporate an altered physical body. Eventually, I successfully negotiated romantic relationships and dealt with numerous bouts of stigmatizing challenges. My experience was filled with trial and error due to a lack of resources available to help with the transition. This experience left me wondering how other survivors negotiate their stigmatizing experiences and sexuality in romantic relationships.

The purpose of this phenomenological inquiry is to articulate the co-construction of meaning within burn survivors' lived experiences of stigma and sexual communication with their romantic partners. This chapter reviews the statement of the problem, the justification and focus of the project, as well as the theoretical and practical implications for the project.

### **Statement of the Problem**

In 2011 the American Burn Association estimated that over 450,000 visits were made to hospital emergency departments by individuals seeking treatment for burn related injuries. A burn injury can be physically, emotionally, and socially devastating to an individual. Yet, the medical field has made astounding progress in treatment of burn related injuries; so much so that mortality rates have dropped to an all-time low (American Burn Association, 2011). Now that survival is not only possible, but probable, research has begun to swing from preventing death to cultivating quality of life (Moi & Gjengedal, 2008).

Quality of life as defined in burn survivor literature refers to the psychosocial adjustment of survivors. Many previous quantitative studies of survivors have focused

their efforts on quality of life (Corry, Pruzinsky, & Rumsey, 2009; Pope, Solomons, Done, Cohn, & Possamai, 2007; Thombs, Notes, Lawrence, Magyar-Russell, Bresnick, & Fauerbach, 2008; Yoder, Nayback, & Gaylord, 2010). Quality of life measures often investigate body image, depression, and social competency (Corry et al., 2009). Additionally, studies on personal characteristics such as resiliency and coping strategies may mediate burn injury and renegotiation of self (Lau & van Niekerk, 2011; Moi & Gjengedal, 2008; Moi, Vindenes, & Gjengedal, 2008; Williams, Davey, & Klock-Powell, 2003). While the research has clearly indicated survivors' issues with body image and social competence (Corry et al., 2009; Pope et al., 2007), only a few studies have begun to address related issues of sexuality and intimacy (Bianchi, 1997; Brubaker-Rimmer et al., 2010; Reddish & Blumenfield, 1984).

Clearly, burn survivors face many communicative challenges when it comes to sexuality. As individuals survive more trauma and live longer lives, how sexuality is communicated to others and experienced after trauma is relevant to communication scholars. Therefore, it is important to examine sexuality within the relational context. Scholars need to understand how individuals manage and negotiate their sexuality after traumatic injuries as well as how romantic partners may attempt to assist survivors through the experience. Broadening the research focus to add the relational partner may add a greater understanding of the sexual experiences of survivors. The following section clarifies the justification and focus of the study by first discussing general knowledge about burn injuries and then moving on to specific struggles survivors face.

## **Justification and Focus**

A change in the physical appearance of the body may lead to potential communication concerns. Therefore, to justify this study, challenges in the physical and social experiences of survivors are presented. First, it is important to understand the burn injury itself and the physical challenges that must be negotiated. Then, the social struggles of survivors can be reviewed such as body image, discrimination, stigma, and sexuality. Each of these areas highlights the potential for relational challenges for survivors and their partners.

### **Burn Injuries**

The American Burn Association reported that the most common cause for hospitalization in the U. S. was fire/flame (Patient Education Institute, 2011). Forty-two percent of burn related injuries are attributed to fire/flame, while scalds accounted for 31% (Patient Education Institute, 2011). Almost 70% of those hospitalized for burn injuries were men, and 68% of all burn injuries were reported to have transpired in the home (American Burn Association, 2011). While these statistics may be surprising, they only give a general sense of the characteristics of burn injuries.

Approximately 18% of all individuals hospitalized for burn injuries are transferred to burn centers (American Burn Association, 2011). Burn centers are specialized units within a hospital that maintain skilled physicians and nurses who focus on burn care and supply unique technical resources for burn patients. These centers are generally very expensive to maintain (in terms of staff and equipment); as a result, there are only a few centers located in each state. On average, patients admitted to a burn center will spend one day there per percent of total body surface area (TBSA) burned

(American Burn Association, 2011). Therefore, a patient with 60% TBSA burned will spend an average of 60 days in a burn center. While time spent in a burn center may be difficult for a survivor, it can be hard on family members as well. Due to the specialization, often burn centers are not located near a survivor's home. Approximately 60% of the US population lives more than one hour away (via ground transportation) from a burn center (Klein, Kramer, Nelson, Rivara, Gibran, & Concannon, 2009), which can add significantly to the stresses partners may feel. Distance may create additional burdens for partners when they have to juggle transportation, finances, childcare, etc. (Sundara, 2011). While the burn center is where the burn experience begins, less is known about experiences after survivors and partners leave the burn center.

Even for studies on the beginning of the burn experience, much of the medical research on burn survivors has been limited to the pathological perspective, in which research is focused on the direct physical effects and care of wounds. For example, a typical medical journal that publishes research specific to burn care (e.g., *Journal of Burn Care and Research*) produces articles dealing with post-operative outcomes, organ failures, physiological responses, metabolism response, and deformity elimination. Adherence to only the medical pathology perspective of burn survivors does not address fully the importance of social concerns (e.g., stigmatizing social interactions, rebuilding identity, sexuality) as they are not directly relevant to wound care. However, with the dramatic increases in survival rates, there are greater numbers of burn survivors who must negotiate many social challenges that burn injuries may cause, such as extensive scarring that disfigures the body. As such, the focus in research needs to expand from not only physical care to also highlight the importance of social competencies and interaction

for burn survivors beyond the time spent in the burn center. As individuals live longer lives with more physical abilities after trauma, the need for greater understanding of how individuals renegotiate selves to live their everyday lives is created. Specifically, this study focuses on burn survivors' sexual lives and stigma and how these experiences are co-constructed with romantic partners. This section of the chapter discusses the social struggles survivors face, such as body image and discrimination to see how these relate to stigma and sexuality.

### **Struggles of Burn Survivors**

Survivors are often left with extensive scarring that changes the landscape of the body. The scarring from the burns and/or resulting surgeries creates a hyperawareness of the new appearance the survivor experiences. Adjusting to new features on the body takes time and support from others (Moi et al., 2008). Research on how survivors experience body image and stigma and how these concepts potentially impact sexuality are discussed below.

**Body image.** Many survivors struggle with body image issues as a result of the scarring. Body image is a major psychological concern that influences many medical conditions as well as how a survivor adapts to their disfigurement (Pruzinsky, 2004). Studies suggest that a burn survivor who considers appearance to be very important will be more likely to have negative adjustment outcomes associated with scarring (Lawrence, Fauerbach, & Thombs, 2006). In fact, dissatisfaction with one's body post-burn is significantly likely to lead to negative effects on quality of life (Fauerbach, Heinberg, Lawrence, Munster, Palombo, & Richter, 2000). A 2007 study on depression and body image revealed that of burn survivors seeking reconstructive surgery, nearly half reported



symptoms of depression, with body image dissatisfaction being the most important predictor (Thombs, Haines, Bresnick, Magyar-Russell, & Fauerbach). Research has shown body image to be an essential contributor to the psychosocial functioning of survivors (Thombs et al., 2008). How an individual copes with their appearance and develops resilience reverberates throughout the adjustment process.

As a result of changing physical features, many survivors discover an identity conflict (Morse & Carter, 1995; Williams et al., 2003). Survivors are often torn between the self they identified with before the burn and the person that exists after the burn. Studies have shown that survivors often initially distance themselves from the body using depersonalized language to maintain self-integrity (Morse & Mitcham, 1998). The burn is an effort to disrupt the connection between the self and the body, and it is up to the survivor to determine how they will come back together. Williams et al.'s (2003) study showed how some survivors will reframe their losses into gains (i.e., when life gives you lemons, make lemonade). However, other survivors in this study were too caught up in the adversity of their embodiment to move on. Survivors' sense of blame and rage was so overwhelming that they were unable to move forward (Williams et al., 2003). How one perceives their body image will impact their overall sexuality. The current study attempts to look at ways in which survivors manage the stigma of burn scars and sexuality concerns that may be linked to body image. The ways in which body image and sexuality are linked to stigma are discussed in the next section.

**Stigma.** Stigma was defined by Goffman (1963) as a discrediting mark on an individual who was of questionable moral status. There are a variety of other scholarly definitions of stigma that will be discussed in more detail in the next chapter; however,

most definitions are quite similar in that they generally refer to a person who is linked to a norm or shared belief about a characteristic, attribute, or behavior that is diminished in certain social situations (Crocker, Major, & Steele, 1998; Major & O'Brien, 2005).

Stigmas are socially constructed (Link & Phelan, 2001; Smith, 2007a), derived from communal identity stereotypes, and shaped by societal ideologies. Stigmatizing discourses are discursively managed by the self and relational partners (Henson & Olson, 2010). As stigmas are perceived to be threats to accepted behaviors, roles, and identities, individuals experiencing stigmatized identities may internalize negative emotions (Major & O'Brien, 2005). Internalization of emotions may lead to greater instances of negative body image for burn survivors (Thombs et al., 2008).

In order to overcome the stigmatizing ramifications of disfiguring injuries that result from burns, research suggests using proactive social strategies, educating others about their condition, and becoming more adaptive (Corry et al., 2009). The current study seeks to understand strategies that survivors and relational partners use to manage the stigma resulting from survivors' burn scars. Many people have never seen a burn injury and will stare at a survivor (in an attempt to understand) without meaning to cause discomfort or irritation to the survivor. Survivors must learn to deal with the communicative challenges that involve their new bodies.

Social situations are often a primary concern for the survivor as they exit the safety of the hospital. These situations may include concern for others' behavior, their own behavior, as well as perceived social support. Communication competence, specifically, is often challenging for survivors initially when faced with questions about their injury (Kammerer-Quayle, 2001).

Survivors must figure out how to communicate with others successfully about their appearance. Kammerer-Quayle (2006), Director of the Image Enhancement and Support Program at the University of California Irvine Medical Center, developed the Behavioral and Enhancement Skills Tools (BEST), designed as an effort to prepare burn survivors for social and body image issues. BEST is a toolkit of written techniques and strategies to assist survivors in feeling confident in social situations (i.e., positive self-talk, maintaining eye contact, and rehearsing responses). While BEST is an amazing tool for burn survivors, it does not serve as a resource for sexuality. Additionally, despite the presence of the BEST toolkit, discrimination against those with physical scars still occurs. Understanding how survivors handle these situations, especially in interpersonal close relationships may benefit other survivors. Additionally, it would be beneficial to learn how relational partners of survivors manage the stigmatizing condition. Therefore, an exploration of survivors and their relational partners' stigma experiences would clarify these gaps.

Studies suggest that burn survivors are faced with stigmatization that defines them as deviant and warranting of dehumanizing behaviors (Beuf, 1990; Porter & Beuf, 1991). Behaviors may be subtle (i.e. avoiding eye contact, ignoring, pity) or more overt (i.e. staring, startled reaction, teasing, whispering, unsolicited questioning, and name calling) (Beuf, 1990; Thompson & Kent, 2001). Research has shown teasing and verbal abuse negatively affect body image and self-esteem over the course of the burn survivor's lifetime (Lawrence et al., 2006; Thompson & Kent, 2001).

According to Bull and Rumsey (1988), those stigmatized for physical maladies experience three effects: poor body esteem, a sense of social isolation, and a violation of

privacy effect. Violation of privacy effect is the ability to be anonymous in a crowd without any undue attention attracted (Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006). Discriminating behaviors such as staring and teasing can also be very stigmatizing for survivors and contribute to negative responses such as heightened anxiety and distress (Fauerbach, Heinberg, Lawrence, Bryant, Richter, & Spence, 2002; Kent, 2000). Based on a previous negative reaction to interaction, a survivor may fear rejection from others and adopt an avoidant coping style (Newell & Marks, 2000). Survivors often report increased self-consciousness, social anxiety, anticipation of rejection, shyness, and apprehension (Kapp-Simon & McGuire, 1997). Combined, these variables may lead to poor communication competence and lead survivors to blame the burn injury for their communication woes, placing survivors in a vicious cycle of dysfunction that may impair quality of life and relationships (Corry et al., 2009).

Due to the stigmatizing nature of a burn injury, the Stigma Management Communication (SMC) model (Meisenbach, 2010) was selected as a framework to explore the ways in which survivors and their partners manage potential stigmatizing messages. This typology of SMC strategies was created to reveal the co-constructed nature of the stigma management process by both stigmatizers and the stigmatized. The typology organizes stigma management strategies “into four quadrants based on individuals’ acceptance/denial (a) of the existence of a stigma and (b) of the stigma’s applicability to that individual” (Meisenbach, 2010, p. 268). Thus, SMC is poised to help make sense of the stigmatizing experiences reported by burn survivors and their partners.

The SMC model is a newer theoretical contribution to stigma literature. As such, using the theory will help determine the applicability of the model and the strategies

listed within the quadrants. Not only will this study be able to consider the usefulness of the SMC model, it also has the potential to further stigma literature by focusing attention on how the model works in assessing the interpersonal relational context. Most stigma literature looks at the stigmatized and/or the stigmatizer. However, this study focuses on burn survivors and their partners' stigmatizing experiences, thus enhancing understanding of the relational context into the stigmatizing situation.

**Sexuality.** In addition to problems managing stigma messages, individuals with visible skin abnormalities, such as burns, often have more problems connecting with others sexually (Brubaker-Rimmer et al., 2010). Changes in body image and self-esteem associated with the burn injury are often inseparable from sexuality (Bianchi, 1997; Brubaker-Rimmer et al., 2010; Whitehead, 1993). Research has shown that a positive body image is highly correlated with sexual satisfaction (Whitehead, 1993), indicating that feeling good about one's body would lead to a satisfying sexual encounter. Therefore, poor body image may cause problems with intimacy for survivors as a result of the intersection of the discursive and embodied scar tissue. Sexuality and intimacy are challenging enough without one partner being overly concerned about how their body is being perceived and compared against others (those without burn scars). In addition, the ability to converse with others about sexuality and disability concerns (should the survivor address the scar or not) may be challenging.

While the survivor's body image is not related to size or location of the burn (Thombs et al., 2007), it is subject to constant redefinition from the perception of others and their responses (Whitehead, 1993) much like everyone else. Survivors with very visible and prominent scars, such as on the face, head, and neck, often struggle the most

with issues of sexuality as they do not appear “normal”(Parrott & Esmail, 2010). While Parrot and Esmail’s 2010 study was about burn survivors’ experiences with sexuality, it focused on sexual education and sexual development for survivors burned as children. The current study builds on their perspective by broadening the scope to sexuality experiences for all survivors while adding the perspective of partners.

In sum, survivors have many tools at their disposal to negotiate and manage stigmatizing and sexual experiences. Burn survivors must work harder to initiate relationships when they have prominent physical stigmas such as facial scarring as they do not fit into the typical western notion of what is attractive. In fact, many survivors with prominent facial scarring are viewed as disabled and fall into a common stereotype that disabled individuals are asexual (Anderson, 1992). Nonetheless, burn survivors may be every bit as interested in and capable of sexual relations as the average person. Thus, the current study explores the stigmatizing and sexual experiences of burn survivors and their relational partners. The next section introduces potential practical contributions this study may make.

### **Practical Contributions**

Understanding the stigma and sexuality communication experiences of survivors and their relational partners also has the potential to make several practical contributions. First, sharing the results of the project with survivors and their partners may assist in their communicative lives. For example, information from this study may help survivors and their partners work to improve communication skills that may lead to an enhanced romantic relationship. Second, knowledge gained from this study may increase awareness and understanding of the relational partner’s importance to the survivor’s

social rehabilitation process. While the survivor is often the main focus of attention, the relational partner goes through a tremendous amount of stress as well. Awareness of each of the relational partner's needs may be beneficial to future families of trauma. Additionally, findings may help health care professionals understand how survivors and their relational partners find meaning through their experiences. These understandings may help health care professionals offer improved counsel and treatment for survivors and their partners.

### **Summary**

Burn survivors are faced with enormous and daunting physical and social challenges. In an effort to continue their everyday lives, they work to negotiate these challenges, despite the communicative messages that may disparage them. Using a communicative perspective and phenomenological approach, this study explores the co-construction of meanings between burn survivors and their relational partners regarding stigma and sexual communication.

The rest of this dissertation is organized in the following way. Chapter two lays the groundwork for the study by providing context on the physical experience of surviving a burn injury. Then social experiences of surviving burn injuries are discussed, including sections on experiencing stigma, resiliency, and sexuality. Chapter three discusses the methods used to conduct the phenomenological analysis. The results of participants' interviews are revealed in chapter four and are organized according to patterns of stigma and sexuality that emerged during analysis. Chapter five discusses the findings in relation to theoretical implications and practical applications and offers suggestions for future directions in research.

## **CHAPTER 2: LITERATURE REVIEW**

This chapter offers a thorough review of the literature related to burn survivors, stigma, and sexuality. The purpose of this study is to understand the co-construction of survivors' lived experiences of sexuality and stigma with their romantic partners. Burn survivors are continuously overcoming obstacles to not only survive, but thrive in today's society. With increasing chances of surviving a burn injury, burn survivors must learn to navigate their social worlds with an altered physical body that can create communication concerns. Therefore, this chapter will discuss many of the challenges survivors face after a traumatic burn injury. The chapter begins with a discussion of the physical experiences burn survivors face. This discussion introduces the types of burns experienced as well as corrective medical procedures. Next, the chapter introduces stigma communication as it relates to survivors and discusses sources of stigma relating to disability and interpersonal interactions. The final portion of this chapter addresses research on sexuality and the sexual experiences of survivors and their partners. To begin, a better understanding of the physical experience of a burn injury is needed.

### **Experiencing a Burn Injury – Physical Aspects**

A burn survivor is quite simply an individual who has survived a severe burn injury (i.e., second and third degree burns requiring skin grafts). A burn injury damages the skin tissue, which is the body's largest organ. Depending on the severity of the damage, burns are divided into three degrees. First and second degree burns are generally very painful as they affect the outer layer of skin called the epidermis. Second degree burns may also damage the dermis, which is the inner layer of skin. Third degree



burns are not painful as they destroy both the epidermis and the lower dermis, which contains the blood vessels, nerves, hair follicles, and glands that lead to sensation.

Individuals receiving second and third degree burns generally require skin grafts to heal (Patient Education Institute, 2011). A skin graft is the surgical process by which a healthy thin swatch of skin is procured from the patient and meshed (i.e., the creation of a series of patterned cuts) to expand its size and prevent accumulation of fluid. Then the graft is surgically stitched or stapled onto the burned area. New blood vessels begin growing and attach to the skin (Barret & Herndon, 2004). Use of the patient's own skin is preferred because it lowers the risk of rejection (Barret & Herndon, 2004). However, sometimes the patient is unable to provide their own skin when their burns cover too much of their own body, which requires doctors to use donors or artificial materials.

With significant damage to the body's largest organ, infection becomes a primary concern. Infections such as septicemia and pneumonia are common among burn patients, resulting in approximately 10,000 deaths a year (Patient Education Institute, 2011). Severe burns also increase metabolism as a natural response to stress on the body (Demling, DeSanti, & Orgill, 2000). The body requires so much energy to respond to the burn injury that it begins to quickly deplete the body's levels of protein (Demling, DeSanti, & Orgill, 2000). Therefore, nutritional support (e.g., protein shakes) is very important for burn survivors (Patient Education Institute, 2011). Despite these medical hurdles, burn centers are currently reporting a 94.8% survival rate, the highest in recorded history. Research in the medical field has come a long way, as 20 years ago individuals with burns covering 50% of their body generally did not survive (Patient Education Institute, 2011).

The experience of a burn center can be described in three phases: resuscitative phase (24 -72 hours after admittance to the burn unit), acute phase (3-14 days post burn), and rehabilitation phase (preparing to leave the burn center) (Reddish & Blumenfield, 1984). The resuscitative phase is characterized by survival. The main focus of physicians and the family is one of surviving the initial trauma. The second phase is acute. During this phase the survivor may become more alert and begins to experience pain. Additionally, survivors become aware of their appearance. The final phase is rehabilitation. This phase prepares survivors to leave the burn center and return home to care for themselves.

After experiencing several skin grafting surgeries, many survivors face permanent scarring of varying extent (Patient Education Institute, 2011). The scarring depends on many factors such as size of burn, location, severity, as well as how well the survivor followed physician orders during rehabilitation. Rehabilitation often requires survivors to wear pressure garments (restrictive spandex-type clothing) to prevent hypertrophic scarring (American Burn Association, 2011). Wearing pressure garments constantly for a year or two post-burn can often be an exhausting reminder of the injury. Failure to wear the garment effectively may lead to more prominent scarring (American Burn Association, 2011). Although reconstructive cosmetic surgeries have advanced significantly over the years, replacing a significant portion of the skin is still not possible. Therefore, scarring is still a challenge survivors must face.

In sum, survivors face a great deal of physical challenges when they experience a burn injury. However, what is apparent is there are a number of issues that burn survivors must contend with beyond the physical burn injury itself. From a

communication perspective, stigmatization, sexuality, and resilience seem to be large interrelated concerns that need further exploration. The remainder of the literature review focuses on the social experiences of surviving a burn.

While stigma is a large part of the survivor's known social experience, sexuality is also important. Sexuality, no matter how it is viewed, is inextricably exposed and linked to stigma. Sexuality is a communicative concept derived from the relationships between sexual identity, sexual behavior, intimacy, and relational status. As a result, how one perceives their sexuality is derived from a combination of these constructs.

Thus, the remainder of the literature review is divided into two main sections: experiencing stigma and experiencing sexuality. The first section begins by discussing how stigma is experienced by survivors. This discussion will include a definition of stigma, reveal how stigma functions, and will detail potential sources of stigma. At the end of the stigma section, a subsection on resilience details what is known about the coping and resiliency experiences of survivors. Finally, the last section of the social experience of survivors, experiencing sexuality is addressed. This section will define sexuality as well as potential sources of sexuality.

### **Experiencing Stigma**

Many scholars agree that stigma is socially constructed (Link & Phelan, 2001; Smith, 2007a) and results from societal-level discourses (Henson & Olson, 2010). Such discourses are shaped by societal ideologies that shift over time and place. Therefore, stigma may also vary across situations and time. Because stigma is so heavily influenced by the cultural environment, the concept has seen a number of distinct classifications. This section of the literature review will serve as an overview of the experience of

stigma. The discussion will focus on the definitions of stigma, its functionality, and current sources of stigma.

### **Defining and Managing Stigma**

For Link and Phelan (2001), stigma is defined “as the co-occurrence of its components- labeling, stereotyping, separation, status loss, and discrimination” (p. 363). Labeling is when individuals distinguish and label difference. Stereotyping occurs when “dominant cultural beliefs link labeled persons to undesirable characteristics- to negative stereotypes” (p. 367). Separation begins when labeled individuals are put into categories, making an “us” versus “them” mentality as way to create physical distance. Once categorized, the labeled individual will experience status loss and discrimination (Link & Phelan, 2001). As such, Smith (2007b) argued that “Stigma, therefore, evolves from stereotypes, that is, formulaic and simplified conceptions of a group and its members” (p. 235). Thus, when people create stereotypes about others, these stereotypes have the potential to develop into stigmatizing perceptions.

In order to further study stigma, scholars have developed many ways to classify the concept. For example, Goffman (1963) divided stigma into three types: body (physical), character (personal), and tribal (social). The body stigma is one that applies to physical deformities such as burn scars. Tribal stigmas refer to the stigmatization of a group such as a race of people or a particular religion. A personal stigma is concerned with the “blemishes of individual character” (Goffman, 1963, p. 4) such as alcoholism. As alcoholism is often viewed in a negative light, individuals with alcoholic tendencies may experience a personal stigma. Additionally, individuals associated with a stigmatized person may also carry a courtesy stigma, just by associating with known

stigmatized individuals. A courtesy stigma may apply to all three types of stigma. This stigma generally occurs within family systems or in occupational roles and thus, is particularly relevant to a consideration of how burn survivors and their partners manage stigma.

Another way to examine stigma has been to partition it into two groups: existential and achieved (Falk, 2001). Existential stigmas are those that an individual has no control over, such as mental illness or age. Achieved stigmas are perceived as earned by the individual and can include stigmas such as homelessness and drug addicts. Individuals earn these stigmas because they are thought to have a choice about entering into the stigmatizing event or characteristic.

Additionally, Goffman (1963) divided stigma into four criteria: visibility, known about, obtrusive, or relevant. A visible stigma is one that can be discerned by others (e.g., obesity, facial scarring). On the flip side, invisible stigmas often can be hidden from others (e.g., HIV, epilepsy). Disclosure of the hidden stigma is dependent upon the nature of the relationship and situation. Therefore, the degree of previous knowledge about a person will dictate what one knows about a stigma's presence. Obtrusiveness of a stigma is determined by how much it interferes with social interaction (e.g., extensive scarring on the legs may prevent one from wearing revealing clothing such as a bathing suit). Finally, relevancy of the stigma is determined by the situation (e.g., going to a public pool may be uncomfortable for one with scars, but might not be as relevant in the home environment). The survivor's total body surface area (TBSA) burned and location may impact the type of stigma situation. For example, a severe burn that is easily hidden by clothing may allow a survivor to live a social life free from stigmatizing

communication. However, a survivor with severe burns on the face or genital areas may experience more stigmatizing situations. Additionally, how a survivor manages the stigmatizing situation will vary. Yet, very little is known about these variances. Therefore, understanding the stigma management techniques survivors use within their communicative relationships will be beneficial.

In 2007, Smith developed a new model of stigma communication in which she defined stigma communication as spreading the word about a labeled person through the community so everyone may react accordingly. Smith (2007a) argued that the stigma message does four things: 1) differentiates a person; 2) develops a way to categorize the different people; 3) links the different individuals to social peril; and 4) places blame on the different people for their different status. These cues encourage production of stereotypes, stimulate affective reactions and action tendencies “which all foster the formation of stigma attitudes” (Smith, 2007a, p. 463). Smith’s (2007a) model gave scholars new ways to conceptualize stigma communication and prompted further stigma research in the communication field.

Based on work such as Smith’s, in 2010, Meisenbach published the stigma management communication model (SMC), which explores two attitudes that relate to the experience and management of stigma: the public’s idea of stigma and the individual’s. Within the model, an individual may accept or reject the public’s belief about the stigma, as well as the applicability of the stigma to the self. For example, perhaps Mary approached Bob and stated that, “Individuals with deformities are gross.” According to the SMC model, Bob would decide how he would respond to the statement based on whether he accepted or challenged the public’s stigmatizing message about

deformities. Bob might also consider the stigma's applicability to himself (whether he perceives himself as having a stigmatizing deformity) before selecting a strategy to respond. The model recognized that individuals have choices about how they could respond to a stigma message and that these choices needed to reflect both internal and external perceptions of whether a person is stigmatized.

Stigma management strategy categories from the model include: accepting, avoiding, evading responsibility, reducing offensiveness, denying, and ignoring/displaying (Meisenbach, 2010). The accepting category includes the following stigma management strategies: passively accepting, displaying/disclosing, apologizing, using humor to ease comfort, blaming stigma for negative outcomes, isolating self, and bonding with stigmatized others. Stigma management strategies for the avoiding category are as follows: hiding/denying the stigma attribute, avoiding stigma situations, stopping the stigma behavior, distancing the self from the stigma, and making favorable social comparisons. The next category from the SMC model is evading responsibility which includes the following strategies: provocation, defeasibility, and unintentionality. Reducing offensiveness includes the following strategies for stigma management: bolstering/refocusing, minimizing, and transcendence/reframing. The denial category includes simple denials and logical denials, which can be further broken down into the following sub-strategies: discrediting the discreditors, providing evidence/information, and highlighting logical fallacies.

Ultimately the SMC model offered a clearer reflection of the decision making process during stigmatization. The model allowed scholars to see how individuals manage stigma communication messages through the use of specific strategies. While

the strategies that this article put forth are theoretically well supported (Ashforth & Kreiner, 1999; Benoit, 1995; Goffman, 1963), they remain untested on empirical data sets (see Medlock-Kylukovski, 2014, for an exception). These SMC strategies may offer a unique insight into survivor and partner communication regarding stigma.

Part of understanding how stigma is experienced by survivors is locating the source of stigmatization. Burn survivors are a valuable population to study as they are forced by trauma to endure identity shifts due to scarring and then dropped into a society that often stigmatizes them. Survivors have to become masters of the discursive element in order to survive socially, as it is through communication that identities are reconstructed. The current project is focused on how stigma is reflected in the communication by survivors and their romantic partners. Therefore, interpersonal interactions as a source of stigma discourses will be reviewed in the next section.

### **Interpersonal Interactions**

How individuals take up and respond to stigmatizing discourses in their daily interactions may vary, therefore it is important to review available scholarship that is relevant to sources of stigma within interpersonal interactions. Clear expectations of others' behaviors during social interaction are important. Kleck and Strenta (1980) conducted a series of studies that attempted to assess individuals' perceptions of the links between negatively valued characteristics (e.g., epilepsy or a prominent scar) and behavior during social interaction. Results revealed that interpersonal expectancies can impact the behavior of others. How individuals expect others to behave can affect their behavior. This expectation creates a causal chain that leads to a change in one's own behavior, which modifies the other's behavior, which then confirms the original



expectancy rather than being connected to the change in one's own behavior (Kleck & Strenta, 1980). Therefore, if a survivor expects their relational partner to be repulsed by their scars, they will most likely enact certain behaviors to cause that kind of reaction by their partner. Kleck and Strenta (1980) argued that "normal individuals do have clear expectations concerning the impact of various physical conditions on dyadic social interactions" (p. 865). Individuals generally don't like to attribute others' deviance to themselves. Attributing deviance onto others is much easier; however, it doesn't have to be the case. In terms of managing stigma, Kleck and Strenta's (1980) study revealed that expecting stigmatization creates opportunity for it to arise in interpersonal relationships. Therefore, expecting a person to stigmatize another individual based on their burn scar sets the stage for the stigmatization to occur.

Within various relational interactions, survivors may encounter a wide variety of stigmatizing remarks. Research has shown that it may be in the best interest of a stigmatized person to ignore prejudiced remarks rather than confront (Swim & Hyers, 1999); however, Shelton, Richeson, Salvatore, and Hill (2006) argued that silence may induce challenges of its own. Potential problems with remaining silent could entail the following: continued prejudiced behavior, feeling of selling out the group, rumination of inaction, and guilt. These notions are based on self-discrepancy theory (Higgins, 1987) in which an individual has three selves: the actual self (as you believe it to be), ideal self (would like to be), and ought self (what it should be). When there is a discrepancy between any of these selves, individuals experience "distinctive affective reactions" (Shelton et al., 2006, p. 68) such as guilt, self-contempt, etc. Therefore, Shelton et al.'s conceptual model shows self-discrepancy is moderated by commitment to challenge

prejudice (activism), which leads to intrapersonal costs (affective and cognitive outcomes) (Shelton et al., 2006, p. 66). This intrapersonal approach is highly dependent on the societal discourses present as well as the interactions one may have with others. Therefore, an individual's decision to confront or ignore stigmatizing remarks is interpersonal and leads one to understand how the stigma experience may be conceptualized as a relational project.

### **Resilience**

Many survivors are faced with stigmatizing situations in today's society. How a survivor navigates the healing process often depends on levels of social support and resiliency (Williams, Davey, & Klock-Powell, 2003). Williams et al. (2003) argued that survivors need quality support from family, friends, and healthcare professionals to build resiliency in themselves to reconstruct their lives. Survivors disclosed that peer support often provides a sense of hope and confidence (Badger & Royse, 2010). Therefore, resiliency gained from peer support may assist survivors in managing stigmatizing situations.

In a study drawn from 39 burn survivors, Holaday and McPhearson (1997) found that "According to the burn survivors, everyone has the gift of resilience within themselves" (p. 355). Coping and resiliency are often used interchangeably (see Snyder & Dinoff, 1999). However, resilience is an adaptive outcome in response to a crisis or trauma whereas "coping refers to psychological and/or behavioral responses that diminish the physical, emotional, and psychological effects of stressful life events" (Williams et al., 2003, p. 55). Coping is the specific behaviors that an individual enacts during a particularly stressful event or trauma such as a burn injury as a way of getting through it.

Resiliency is how one uses the coping skills and other resources to adapt to the traumatic situation overall.

A 2003 qualitative study of eight burn survivors revealed experiences of determination, courage, and compassion, which exemplify resiliency (Williams et al.). The differences in how participants adapted seemed to support the idea that many variables contribute to the adjustment process. For example, the men in the study held strong ties to their occupations; the end of these roles had severe consequences for their self-esteem. However the women, whose injury was unrelated to their occupational status, were able to reframe their loss into a gain. This reframing is reminiscent of a strategy used in the dirty work typology (see Ashforth & Kreiner, 1999). Within the dirty work typology, reframing refers to the transformation of meaning from the negatively construed occupation to something more positive. This reframing transformation can be done in two ways: (1) by infusing the stigmatized occupation with positive worth, or (2) determining that the ends justify the means (Ashforth & Kreiner, 1999). Reframing was one strategy used in the adjustment process that called upon resiliency of Williams et al.'s (2003) participants.

Despite the adaptation differences between men and women in the limited sample, Williams et al. (2003) did offer suggestions for building resiliency: (1) discussing survivor's life pre-burn, (2) assessing stage of recovery and stage of life cycle, (3) exploring social support and self-esteem, and 4) investigating loss of occupational roles. While Williams et al.'s study was exceptional in clarifying resiliency in many ways; it only focused on the survivor's perspective. Their study did not take into account the survivor's relational partner. The current project takes up where Williams et al. left off,

to account for the partner/survivor interaction. A dyadic approach would allow for a wider, relational perspective in the overall experience of resiliency.

One of the elements of building resiliency is social support. Support is given in a variety of ways such as: family, social workers, friends, and other survivors. Social support refers to the communication that helps manage uncertainty and increase the perception of control in one's life (Albrecht & Adelman, 1987, Albrecht & Goldsmith, 2003). While there is a wealth of social support research in the interpersonal literature (e.g., Albrecht & Adelman, 1987, Albrecht & Goldsmith, 2003; Goldsmith, 2004; Rains & Keating, 2011), the current review highlights only the research most directly related to the experiences of survivors.

In a study of peer support, Badger and Royse (2010) argued that encouraging survivors to engage their strength, determination, and motivation helps them establish new identities and begin to successfully navigate challenges. Peer support has been found to offer a sense of belonging and affiliation to those with burn injuries (Badger & Royse, 2010). There are many peer groups available for support (i.e. World Burn Congress, Camp Courage, Hoosier Burn Camp, Victim2victor), depending on the survivor's specific needs.

Additionally, special programs exist to assist children who are burn survivors with building resiliency. These programs offer re-entry education for classmates of young survivors returning to school (Phoenix-society, 2011). Educational programs involve a speaker entering the survivor's classroom and speaking to the children about burn injuries in an attempt to minimize the stigmatizing behaviors. Often children use stigmatizing behaviors because they lack knowledge about what they see and do not know the lifelong

effects their behaviors may have (Phoenix-society, 2011). Encouraging survivors at all ages to build resiliency as they move past their trauma is the goal of many support programs. However, the existing resiliency research on survivors is limited to the perspective of the survivors. Therefore, this study will examine the relational context of resiliency by exploring how resiliency is used to manage stigma for survivors and their partners.

### **Summary of Stigma and Related Research Question.**

Stigma shapes and is shaped by the cultural environment surrounding an individual. Stigmatization is a natural function of social life in which individuals label others as a way to mark people. Often this marking is done on the basis of visual disability, as the disabled often appear to be different and therefore a potential challenge or threat. Burn survivors fit into this disability discourse as they are often defined by their disfigurement/scars. Much like individuals who bear a cerebral palsy diagnosis or a missing limb, burn survivors are defined by their limiting characteristic that sets them apart from others in a negative manner. Burn survivors are unique in that each comes by their characteristic due to trauma of some sort (i.e., fire, scald, etc.) and must redefine their identity based upon the potentially stigmatizing characteristic.

This study is focused on the communicative struggles survivors and their partners face after a traumatic burn injury. Developing a better understanding of the stigmatizing experiences within the relational context of survivors and their partners will expand current research and potentially assist future survivors in negotiating stigmatizing situations. To better understand how survivors and their romantic partners negotiate potentially stigmatizing situations, the following research question was developed:

RQ1: How are stigmas reflected in/managed by burn survivors and their romantic partners?

### **Experiencing Sexuality**

While stigma is an important area of research on burn survivors and their partners, so is sexuality. Research has indicated that romantic partners had sexual concerns related to their survivors' diminished sex drive and performance anxiety (Reddish & Blumenfield, 1984). Additionally, many wives in this particular study were concerned about being revolted by the sight of their husbands' wounds (Reddish & Blumenfield, 1984). Such reactions may impact the survivors' understanding of their own sexuality, becoming a part of their experience as a survivor that is particularly relevant to their romantic relationships. As a result, the need to study and discuss communication about sexuality as it relates to survivors and their partners is imperative to relational and survivor scholarship.

### **Defining Sexuality**

Currently much of the research in communication uses the term sexuality fairly loosely in that it is easily exchanged with other terms such as sex, sex acts, and sexual relations (e.g., Montesi, Fauber, Gorden, & Heimberg, 2011; Svetlik, Dooley, Weiner, Williamson, & Walters, 2005). Scholarly distinctions between sexuality and sex itself are scarce, which leads to confusion about a general picture of how the concepts relate to one another. A review of sexuality definitions helps generate a clearer understanding of the concept. Reiss (1989) offered a sociological definition of sexuality as "the erotic arousal and genital responses resulting from following the shared sexual scripts of that society" (p. 6). While this definition is useful, it does not encompass the intricacies of

the concept related to emotion and identity. Sexuality is connected to more than physiological reactions and social scripts within one's life. Psychologists, Aron and Aron (1991) argued "sexuality is the constellation of sensations, emotions, and cognitions that an individual associates with physiological sexual arousal and that generally gives rise to sexual desire and/or behavior" (p. 27). This definition is much broader than Reiss's definition and gives one a sense of additional variables at play; however, it is limited in that it does not include aspects of identity and relational status.

Jackson and Scott (2010) argued that sexuality encompasses needs, behaviors, and identities considered to be erotic. Jackson and Scott (2010) went on to say that "sexuality is not limited to 'sex acts' or to sexual identities but involves feelings and relationships, the ways in which we are or are not defined as sexual by others and the ways in which we so define ourselves" (p. 2). The way in which Jackson and Scott defined sexuality indicates the concept is a larger umbrella term that incorporates many other sexual variables and is not synonymous with other sexual terms such as sexual behavior. Jackson and Scott's definition of sexuality is particularly strong in that not only do they position sexuality as influenced by society; they also point out the influences of one's own perceptions. While this definition overall is very strong, a major limitation is that it does not highlight the communicative construction of sexuality. Therefore, a new communicative definition of sexuality will be constructed based upon Jackson and Scott's definition.

For the purposes of this project, sexuality will be defined as the communicative experience of the intersections among an individual's sexual identity, sexual behavior, sense of intimacy, and relational status. This definition is more relevant to the current

study because it accounts for the social construction of sexuality; therefore, it is inherently communicative. Additionally, each of the concepts that works together to create sexuality is also communicative as it is constructed within a cultural context. Therefore, sexuality is experienced communicatively. By constructing sexuality as communicative, scholars may begin to understand the intersections of the components in a new light, allowing for more opportunities for scholarly exploration.

Now that sexuality has been defined, each of the intersecting components will be defined and discussed. First, literature on sexual behavior will be discussed as it relates to burn survivors. Intimacy will then be examined as it relates to other concepts of sexuality. Next, sexual identity will be redefined and introduced as a multidimensional construct rather than as a singular construct of sexual orientation. And finally, relational status will be reviewed as it connects to sexuality and survivorship.

**Sexual behavior.** While sexuality is the communicative experience of the intersections among an individual's sexual identity, sexual behavior, sense of intimacy, and relational status; sexual behavior is probably the most visible component in one's mind due to constant societal reminders (i.e., media messages of sexual activity). The current study will be discussing how participants talk about the actual sexual behaviors of burn survivors stemming from their physiological and psychological desires. Understanding survivors' communicative constructions of their sexual behavior is a critical aspect of understanding their overall experience of sexuality. Gaining knowledge about survivors' sexual behaviors enables scholars the ability to view some of the challenges survivors may face.



Many scholars are content to define sexual behavior as engaging in genital contact (Cupach & Metts, 1991; Sprecher & McKinney, 1993). However, the communication that occurs before, during, and after genital contact as well as social scripts are also a part of sexual behavior. Without detailed knowledge of one another, partners often must rely on cultural scripts to determine appropriate sexual behaviors (Baxter, 1987). For example, women often engage in extended physical closeness to encourage male initiation of sexual behavior (Cupach & Metts, 1991). Additionally, sociobiological theories indicate that men generally initiate sexual activity while women generally control the actual occurrence of sexual activity (LaPlante, McCormick, & Brannigan, 1980; McCormick, 1979). Therefore, communication is used to negotiate the occurrence of sexual behavior as well as the manner of sexual activity (i.e., safe sex talk) (Cupach & Metts, 1991).

Sexual behavior is also closely tied to other aspects of sexuality such as intimacy. Engagement in sexual activity such as foreplay (i.e., kissing, touching) leads to increased arousal. Increased arousal involves complex emotions such as hormones and imagery moderated by experience (Strongman, 1987). In a 1987 study, married couples were asked about their sexual activities (Metts & Cupach). Men reported themes of frequency and arousal, while women were more likely to report themes of comfort, communication, and specialness. These findings suggest that men are more likely to view the sexual activity in physical terms whereas women tend to view sexual behavior as intertwined with intimacy (Cupach & Metts, 1991). Therefore, survivor sexual behaviors may be gendered.

**Intimacy.** While intimacy is closely connected to sexual behavior, it is still a distinct concept of sexuality with many scholars studying its communicative connections (Aron & Aron, 1991; Burgoon & Hale, 1984, 1987; Schaefer & Olson, 1981; Theiss & Solomon, 2007). Schaefer and Olson (1981) have defined intimacy as sharing physical and emotional experiences and feelings of closeness. The definition of intimacy covers a lot of ground; however, each component appears vague and hard to identify conceptually. For example, the concepts of emotional experience and a feeling of closeness are challenging to differentiate between. Therefore, it would make sense to develop a definition of intimacy in which the concepts were distinctly clarified. Clarification of intimacy was later made more distinct within Burgoon and Hale's (1984, 1987) seven fundamental themes of communication. Intimacy was defined as a multidimensional construct in which individuals communicate affection, inclusion, trust, depth, and involvement. Intimacy is often communicated through self-disclosure, displays of affection, and immediacy (Burgoon & Hale, 1987). Burgoon and Hale's intimacy scale has been tested many times in communication scholarship (see Kelley & Burgoon, 1991). While this definition of intimacy is a useful beginning, this project must focus specifically on sexual intimacy.

Communication scholars have defined sexual intimacy as cognitive, emotional, and physiological reactions to sexual arousal (Aron & Aron, 1991; Metts, Sprecher, & Regan, 1998). Outcomes of sexual intimacy have been characterized by relationship consequences, sense-making, and emotional reactions, which may all be influenced by communication about sexual encounters (Theiss & Solomon, 2007). Theiss and Solomon (1997) argued that many forces influence sexual intimacy such as (a) an individual's

sexual attitudes, (b) degree of relational intimacy, (c) one's goals for the sexual encounter, and (d) one's biological sex (i.e., male or female). Motivating factors for sexual intimacy include (a) experiencing feeling of value from a partner, (b) showing value for others, (c) nurturing others, (d) increasing one's personal power, (e) feeling a partner's power, (f) discharging stress, (g) feeling pleasure, and (h) procreation (Hill & Preston, 1996). As emotion is a salient force within the sexual experience, sexual intimacy may facilitate a range of emotional experiences such as happiness, guilt, fear, sadness, anger, fear, and surprise (DeLamater, 1991; Haselton & Buss, 2001; Theiss & Solomon, 2007). This range of emotions may be experienced within the relational interactions of survivors and their partners. How a survivor and their partner perceive this sexual intimacy may affect their sexuality overall, leading to consideration of sexual identity as part of sexuality.

**Sexual identity.** Many scholars have restricted their definition of sexual identity to sexual orientation (Tabatabai, 2012; Weeks, 1985), thereby privileging the study of homosexuality when considering sexual identity. It is important to understand that sexual identity is not limited to consideration of sexual orientation. Scholars adhering to a multidimensional sexual identity conception such as Baltar (1998), have defined it as an aspect of one's self-concept that includes a collection of cognitions and emotions that correspond to an individual's gender identity, sex-role identity, and sexual attraction. While this definition broadens the notion of sexual identity beyond sexual orientation, it is still limited to self-perceptions.

Brekhus (1996) addressed this limit when he argued that sexual identities are assigned to others within a social context based on six specific dimensions: quantity of

sex, timing of sex, level of enjoyment, consent, orientation, and social value. Within these dimensions, individuals tend to mark sexual identities in opposing extremities of “normal” and “abnormal” (Brekhus, 1996). This definition allows for a very specific typology of sexual identity with a social context while allowing for fluidity among dimensions. While the concept is clearly a social one, it does not highlight relational contexts.

Based on Brekhus’s (1996) definition, a new definition of sexual identity was constructed for this project. Sexual identity is a social co-construction of the self that develops from a compilation of sexual satisfaction, gender roles, orientation, and body image. This definition of sexual identity will guide the remainder of the study and each of the components will be further discussed and defined below.

***Sexual satisfaction.*** The first component of sexual identity is sexual satisfaction. Sexual satisfaction is essentially how happy one is with the sexual nature of their relationship. Studies often show that satisfying relationships give way to satisfying sexual encounters (Sprecher, 2002; Theiss, 2011); however, negative characteristics such as emotional distancing and feeling unloved may lead to decreased satisfaction (Davidson & Darling, 1988). Theiss (2011) found that relationships characterized by direct sexual communication were more sexually satisfying than those characterized by indirect sexual communication. However, not all direct communication may lead to sexually satisfying encounters. Individuals that conform to traditional gender roles may find direct sexual communication violates their prescribed gender role. For example, women in traditional gender roles are expected to be sexually passive; therefore, speaking up about their sexual desires may be face threatening to their partner (Theiss, 2011). Thus, how one

communicates regarding their sexual relationship impacts the satisfying nature of their relationship overall. For this project, sexual satisfaction is one of four sections of sexual identity. Satisfaction may be one area in which survivors and their relational partners may be able to articulate changes in their relationship as it relates to sexual identity.

***Gender roles.*** Gender roles are the cultural perception of specific attitudes, feelings, and behaviors and the degree of one's masculinity or femininity that pertains to one's sex (Lorber, 1994). Gender is a social construction that begins at birth. Babies are assigned a male or female gender according to their sexual genitalia, then dressed, named, and spoken to using various gendered markers (Lorber, 1994). West and Zimmerman (1987) argue that gender is not a state of being, rather it is a practice, and people are constantly "doing gender." This practice of doing gender is organized in that individuals are able to do gender appropriately by ascribing to cultural standards. These cultural standards are constantly evolving in terms of what it means to be a man or a woman. Children learn their gendered roles from parents very early and reproduce them throughout their lives. These roles heavily influence how individuals interact with one another with regard to providing a social script to enact (Lorber, 1994). Failure to enact the social script causes confusion during relational interactions. This failure does not require that everyone follow the script, rather, awareness of social expectations can ease the relational interaction. Consequently how an individual does gender has the potential to influence their sense of self and their sexuality, thus making gender roles an integral part of one's sexual identity. As role changes are common during hospitalization (Reddish & Blumenfeld, 1984), how survivors and their partners negotiate new roles may impact a survivors sexual identity overall.

**Orientation.** In American society, orientation simply refers to the type of partner(s) an individual is attracted to. Generally orientation is marked as a dichotomous category in which sexual identity was either heterosexual or homosexual. With the increasing need to provide other categories such as bisexual or transsexual, redefinition of the category is sorely needed. Scholars have increasingly seen the need to dismiss the binary in favor of a continuum (Baltar, 1998; Brekhus, 1996). Understanding sexual orientation as a fluid concept rather than binary allows scholars opportunities to explore subtleties not only within relationships but also the self. Sexuality within the self may be perceived as fluid as well. How one defines their sexual self may change depending on a given situation or time. For example, Brekhus (2003) found that one's sexual identity was practiced differently for different individuals. Specifically, homosexual sexual identities were expressed uniquely depending on time and location. The marking of orientations simply highlights difference rather than sameness. Whether one's sexual orientation is marked or not, who one is attracted to plays into one's overall sense of sexual identity.

**Body image.** The final component of sexual identity is body image. Body image is more than an individual's perception of their physical appearance; it also includes perception of bodily function, level of competence, as well as sensation (Pruzinsky, 2004). Many scholars also find it challenging to measure body image as it is a subjective experience that is often dependant on many factors such as body image investment, sensitivity to sensations, resilience, and personality (Pruzinsky, 2004). As body image is influenced by many personal and contextual variables, it is important to highlight body image's ability to be experienced in the moment and its fluidity (Pruzinsky, 2004). How

an individual feels about their body may change in a given moment, situation, or even with a particular person. For example, a survivor may have a negative image of their body with their partner and yet maintain a healthier body image when their physician is present.

While the survivor may struggle with body image due to changed physical appearance, research suggests families of the survivor struggle with their partner's body image as well (Goyata & Rossi, 2009; Shenkman & Stechmiller, 1987). Many family members express concerns about physical appearance especially when skin grafting is involved (Reddish & Blumenfeld, 1984) and express unrealistic expectations (Sundara, 2011). Other research has even indicated that families are more concerned with physical appearance than survivors (Goyata & Rossi, 2009; Shenkman & Stechmiller, 1987). Physical changes to the body matter tremendously to both the family and survivor.

The perception of one's body is influenced by the cultural and social environment in which an individual is located (Jackson & Scott, 2010). The body does not stand separate from the mind. Jackson and Scott (2010) argued that "sex entails embodied selves engaged in embodied social activity and embodied interaction." Therefore, the body cannot be separate from the self. One's own perception of their body is not the only viewpoint of concern; many individuals also consider how others perceive their body as well.

Self objectification theory states that individuals tend to internalize and define the self as they appear to others (Fredrickson & Roberts, 1997). Because of this heightened sense that their body is on display, individuals often monitor their appearance. Fredrickson and Roberts (1997) argued that continuous body monitoring expends

valuable mental resources, which leaves less mental energy for focusing on sex. In fact, spectating is a style of self-focus that entails being intensely aware of one's appearance rather than absorbed in the sensory facets of sexual activity (Masters & Johnson, 1970). Distraction concerning appearance may disrupt sexual functioning (Karafa & Cozzarelli, 1997) and diminish sexual esteem (Dove & Wiederman, 2000). Therefore, this research has shown how perceptions about one's body cannot be separated from the body itself. Furthermore, rumination about these perceptions creates challenges for sexual communication. As a consequence, body image is an integral portion of one's sexual identity.

As previously stated, sexual identity is a co-construction of the self that is a compilation of sexual satisfaction, gender roles, orientation, and body image. Each of these constructs works together to conceptualize the sexual identity of survivors and how it is manifested within the romantic relationship.

**Relational status.** An individual's relational status is the final component of sexuality to be discussed. As previously noted, sexuality is the intersection among sexual behavior, intimacy, sexual identity, and one's relational status. Determining an individual's relational status is not as simple as checking off a box; relationships can be challenging. Within interpersonal research (Schutz, 1958; Scott & Powers, 1978) there are three basic types of relationships: role relationships, interpersonal relationships, and close relationships. Role relationships are often temporary and characterized by specific functions such as exchanging money or food; whereas interpersonal relationships are described as having unique interaction patterns. Interpersonal relationships also require individuals to influence one another in meaningful ways such as providing emotional



support and engaging in self-disclosure. Close relationships have all of the same qualities of interpersonal relationships with the addition of emotional attachment, need fulfillment, and irreplaceability. Affection, inclusion, and control are three of the most central needs that may be satisfied within close relationships (Schutz, 1958). Emotional connectedness and fulfilling critical needs such as love and social belonging are critical functions of maintaining a close relationship (Schutz, 1958). Behavioral interdependence becomes more enduring and diverse in close relationships as partners work towards shared goals (Scott & Powers, 1978).

Scholars agree that relationships are constituted through communicative behaviors with others (Baxter, 2011; Capella, 1988; Wilmot, 1995). Furthermore, relationships are defined through recurring interaction (Wilmot, 1995). Specifically, relationships are created and maintained through the interplay of discourses (Baxter, 2011). Therefore, every time partners interact, their communication works to redefine their relationship in new ways. Sometimes initial sense-making tasks may be large like when a relationship is new and partners are working to figure one another out; however, relational sense-making may require less work in more established relationships. Thus, relationships are not static containers in which communication occurs; rather relationships are defined by and define the communication that occurs between parties.

Concerns with sexuality also occur within other types of interpersonal relationships such as healthcare providers. Research has shown that healthcare professionals are not addressing the survivors' intimacy and sexuality needs (Brubaker-Rimmer et al., 2010). Brubaker-Rimmer et al. (2010) found that while 95% of healthcare professionals agreed that survivors should not be responsible for initiating a conversation

about sexuality, only half of those professionals would discuss sexuality if initiated by the patient. Furthermore, only 14% of those professionals felt comfortable having said conversations. What this study brought to light was that if a particular staff member was not designated to speak about sexuality and intimacy matters, the conversation was likely not to happen. Additionally, other survivor studies have intentionally left out questions relating to sexuality due to their explicit nature (Sundara, 2011). The concern is that sexuality for survivors and their relational partners is not being adequately discussed, either in the medical setting or in the survivor literature. Therefore, this study seeks to begin fulfilling this gap by exploring the sexual experiences survivors and their partners face.

Understanding the fluidity of relationships allows one to see the tenuous connections between relational status and sexuality. How one person is connected to another person and the dynamics of their interactions has potential to not only change the relationship but also one's sexuality. Sprecher and Cate (2004) found that married couples experience greater levels of sexual satisfaction than cohabitating couples. Therefore, relational differences such as marriage can affect sexuality. Even within marriage or long-term relationships, small nuances may affect sexuality, such as who initiates sexual activity. Sexual interactions are most often initiated by men in marital and cohabitating relationships (Cupach & Metts, 1991). The most sexually active and satisfied relationships are ones in which individuals enjoy relating with their partner in various other life activities (Donnelly, 1993). However, couples that share few activities often report unhappiness and sexually inactive marriages. This finding indicates that sexual activity is a vital resource to long-term relationships.

It is important to understand what kind of sexual activity occurs within the romantic relationship of survivors and their partners. Frequency of sexual behavior decreases for a number of factors (i.e., length of the relationship, marital unhappiness, increased age, and potential to separate) (Donnelly, 1993). Additionally, Call, Sprecher, and Schwartz (1995) found a decrease in rates of marital sex due to habituation and increased age. Habituation occurs when a couple has moved beyond their honeymoon period and the sex gradually declines. Frequency of sexual behavior also decreases as the couple increase in age. Sometimes this decrease in sexual activity is due to medical problems. However, sexual activity in long-term relationships has been shown to improve over time despite medical concerns (Hinchiff & Gott, 2004). Quantity of sexual encounters does not matter as much as the quality of the encounter, as sexual preferences are learned over time. While research has demonstrated the potential for positive sexual relationships despite trauma, little research has actually investigated sexuality in survivors and their relational partners. The current study explores the relational aspects of sexuality with survivors and their partner.

Sexuality is seen as an important component of the relationship by many individuals. In fact, all but two participants out of 28, in a long-term relational study by Hinchiff and Gott (2004) viewed sexual relationships as a positive addition to their overall quality of life. The benefits of a sexual relationship included self-confidence and a greater bond between themselves and their relational partner. As a result, relational satisfaction may be an essential characteristic of sexual activity. A 2005 study on marital and sexual satisfaction, found couples with good communication were more satisfied with their marriages (Litzinger & Gordan). Additionally, when communication was

good, sexual satisfaction did not contribute to marital satisfaction. However, if communication was poor between partners, sexual satisfaction contributed to marital satisfaction. Therefore, poor communication does not completely derail a relationship. Satisfaction with one's relationship may still be possible if the couple have a satisfying sexual life.

However, sometimes in life a trauma (i.e., burn injury) may occur which disrupts a couple's sexual relationship. More specifically, a qualitative study by Reddish and Blumenfield (1984) explored 25 wives' reactions to their spouse's severe burn injuries within three phases. In the resuscitative phase (24 -72 hours after admittance to the burn unit), women often idealized their relationship and the personal qualities of their partners. The acute phase (3-14 days) initiates survivor recognition of challenges with pain and disfigurement. Wives often reported feeling helpless and guilty. As a result of challenging visits with the survivor, partners often felt angry at their spouse for disrupting their life; however, this anger was often displaced towards the burn care staff. The final reaction phase is known as rehabilitation (preparing to leave the burn center). Many of the survivors' spouses were concerned with their partner's sexual response. Many relational partners had already noted diminished sexual drive during the previous phases and were concerned about how they might handle performance anxiety. Beyond the sexual satisfaction of these relational partners, the Reddish and Blumenfield study (1984) also found disruptions within relational roles. When the survivor was incapacitated, the partner had to take on new roles, which often gave many wives a stronger sense of confidence and independence. While these findings are specific to male survivors and female partners, many of the relational challenges should be present if the sexes were to

be altered. What these findings do not focus on are the sexual challenges that actually occur in relationships once the survivor returns home. Therefore, this study will extend previous research by talking to survivors and their partners about sexuality experiences after they are released from the burn center.

### **Summary of Sexuality and Related Research Question**

This study is focused on the stigmatizing and sexual communicative struggles survivors and their partners face after a traumatic burn injury. While the research on sexuality at large is impressive, the focus on sexuality after trauma is lacking. Developing a better understanding of the sexual experiences within the relational context of survivors and their partners will expand current research by exploring the sexual communication after rehabilitation and potentially assist future survivors in negotiating relational lives. To better understand how survivors and their romantic partners negotiate sexual communication the following research question was developed:

RQ 2: How is sexuality enacted/co-constructed by burn survivors and their romantic partners?

### **Summary of the Study and Research Questions**

The communicative sources of stigma and sexuality have not been discussed as important elements of the survivor/partner experience. With the exception of a few studies, much of the survivor research has been limited to quantitative studies that have chosen not to focus on sexuality. Furthermore, the literature that does highlight sexuality is limited and focuses on the survivor rather than the relational partner. Therefore, the goal of this study is to explore the stigma and sexual experiences of survivors and their

relational partners. To carry out this goal, the following two research questions have been developed:

RQ 1: How are stigmas reflected in/managed by burn survivors and their romantic partners?

RQ 2: How is sexuality enacted/co-constructed by burn survivors and their romantic partners?

## **CHAPTER 3: METHODS**

The purpose of this chapter is to explain the methods and methodology that were used to carry out this study. The chapter begins with a discussion of the assumptions within the interpretive paradigm. Hermeneutic Phenomenology is then introduced as the primary methodology that guides this research project. Next, the researcher's standpoint acknowledges the researcher's position and bias within the current study. It is imperative that personal connections be identified to understand the potential for researcher influence. The data collection process is then described in detail. Finally, data analysis procedures are discussed. An interpretative approach, incorporating in-depth interviews, is used to attend to the voices of burn survivors and their relational partners. In line with the interpretive tradition, the researcher seeks to understand survivor/partner experiences of stigma and sexual communication through an emergent design and analyzes data with an inductive approach.

### **Interpretive Paradigm**

The interpretive paradigm is one in which understanding is achieved through observing lived experience (Lindlof & Taylor, 2002). In the current project, the interpretive paradigm allows the researcher to attend to burn survivors and their relational partners' communicative experiences with stigma and sexuality. An inductive or -emic approach to research is often used when the researcher wishes to draw conclusions from specific observations or interactions (Creswell, 2007). Interviews or observations are generally the first step of the inductive approach. Then general patterns are located within the data, tentative claims are made and confirmed with participants, and finally conclusions are drawn (Creswell, 2007). Denzin and Lincoln (2005) used the metaphor

of a bricoleur when describing qualitative researchers, as they must use the strategies and methods of their craft to reveal the emergent design of a project.

The interpretive paradigm is also appropriate for this project as it accounts for multiple co-created realities across survivors, their partners, and even the researcher. Individuals are distinct, with a wide variety of lived experiences. Guba and Lincoln (2005) argued that reality is local, and that participant and researcher co-create reality as they form relationships through the interview process. Thus, the researcher's presence naturally contributed to the co-creation of meaning within the interview itself.

Through qualitative research, I engaged participants to uncover the co-constructed meanings of sexuality and stigma within the interactions of the survivor/partner relationship, and to interpret findings across participants. Specifically, interviews allowed the opportunity to listen to participants attentively, make interpretations, and suggest common themes.

Within the interpretative paradigm, there are a variety of methodologies a scholar may use to understand a particular phenomenon. Since the goal of this study is to uncover the communicative experiences of survivor/partner interactions to determine how meaning is created, a phenomenological approach was the best fit. The next section discusses a phenomenological methodology and how it applies to this study.

### **Hermeneutic Phenomenological Methodology**

Van Manen (1990) stated that hermeneutic phenomenology is a method for understanding the meaning behind humans' everyday experiences. A phenomenological approach allows the researcher to focus on individuals' experiences of a phenomenon in an attempt to understand the phenomenon itself. Hermeneutic phenomenology focuses



on the interpretation of the meaning of lived experiences (van Manen, 1990), while transcendental phenomenology focuses more on the description of lived experiences (Moustakas, 1994). Analyzing a variety of experiences helps the scholar locate a universal essence or meaning of the phenomenon (Creswell, 2007; van Manen, 1990). A clearer image of the phenomenon should come into focus after reviewing each of the individual experiences.

According to van Manen (1990), there are eight key elements of hermeneutic phenomenology. First, phenomenology is the study of lived experience. Lived experience is conceptualized as existing in a pre-reflective world (i.e., the world as one immediately experiences it). The goal of phenomenology is to understand the meaning found in these everyday moments. Second, consciousness dictates lived experience. If a phenomenon may be conceived of or thought of, then it may be considered a lived experience. Third, phenomenology is the study of essences. The essence of a particular thing is an attempt to understand the very nature or meaning of a given lived experience, such as a burn injury. Fourth, phenomenological research describes meanings as individuals live them. One's perspective of a given experience may have a different meaning than another individual's. For example, a survivor may experience resentment for the burn injury situation, however their relational partner may feel the survivor should accept the situation and move on. Fifth, phenomena are studied from a human scientific perspective. Therefore, lived experiences are studied in ways that are systematic, explicit, self-critical, and intersubjective. Sixth, phenomenology is characterized by thoughtfulness. Thus, the phenomenological researcher must practice tactfulness and act responsibly. Seventh, phenomenological research assists in building the knowledge of

what it means to be human. As meaning is found in one's everyday lived experience, so is the element of what it means to be a burn survivor. Understanding what it means to be a survivor entails developing an understanding for the struggles survivors encounter in their everyday lives. And finally, the eighth element of phenomenological research is poetry. Van Manen (1990) argued phenomenology is a poetizing project because one cannot separate the research from the results, because the study itself is the result.

A transcendental phenomenological approach requires the researcher to engage in *bracketing* (Moustakas, 1994). Bracketing for many scholars involves setting aside preconceived notions and past experiences with the phenomenon. However, other scholars (Kvale, 1996; Orbe, 1998) argued bracketing merely indicates acknowledging the researcher's preconceived notions. Kvale (1996) reasoned that bracketing does not involve an absolute absence of presuppositions, but rather a critical analysis of one's own presuppositions (p. 54). The researcher's standpoint is acknowledged and looks to these assumptions to understand how they may impact the study. In keeping with a hermeneutic phenomenology, this study follows Kvale's notions, identifying the researcher's presuppositions within the section entitled researcher's standpoint. Individuals do not experience a phenomenon in its entirety. Rather, each individual encounters the phenomenon at a fraction or reduction of the way the phenomenon is experienced (van Manen, 1990). The researcher must keep this notion in mind as they piece the experiences together to form an overall picture of the phenomenon. As part of the bracketing process, I offer a critical analysis of my presuppositions and standpoint in relation to the proposed project.

### **Researcher's Standpoint**

As a researcher's analysis cannot be separated entirely from their subjective biases (Creswell, 2007), it is imperative to acknowledge my position and the potential for interaction with the study. As a burn survivor, I entered the study from a position with insider knowledge and recognized that this position may impact the research. Creswell (2007) noted that the researcher is the instrument in qualitative research. As such, the location of said instrument, the researcher, is a valuable part of the interpretative process. Therefore, I reveal how my background and interests guided this project and had the potential to impact the data collection process.

When I was 17 years old, I passed out during an early morning shower and received second and third degree burns to 60 percent of my body. To this day no one knows why I passed out or how only the hot water was running. I spent approximately six weeks in the hospital, within a specialized burn center. During my hospital stay, I received multiple skin graft surgeries and almost died from infection. After the initial four weeks in the intensive care unit (ICU), I was released to a regular hospital room within the burn center. In this room, the focus of care changed from survival to preparing to leave the hospital. These preparations involved everything from wound care, an introduction to pressure garments, a first look in the mirror, and a discussion about how to handle staring. What I didn't realize at the time was that there was no conversation about intimate relationships or sexuality. I was only 17 at the time of my injury; however, such relationships and sexuality are still important facets of one's everyday relational life.

For burn survivors, discussing sexual intimacy can be exceptionally challenging as they are faced with numerous physical changes (Brubaker-Rimmer et al., 2010). I remember looking at all of my scars and thinking that nobody could ever possibly find me attractive enough to date. Survivors must negotiate their physical landscape as well as their mental concerns. After the burn injury, I had to re-conceptualize my identity. My outward appearance had changed, and therefore, internally I had to adjust for that change. For example, my reactions to others became more subdued. I used to be very outgoing, and after the burn I became more withdrawn, almost afraid to interact with others as I thought they might say something negative or derogatory. Therefore, my sexual identity also changed. Again, before the burn I was only in the beginning stages of sexual activity and forming a sexual identity, but that sexual identity matched my personal identity in that I was very outgoing, personable, eager to please, and yet stood up for my thoughts. Afterwards, my sexual identity became very reserved and deferential. My sexual identity continued to evolve as I became more experienced and gained more information about sexual intimacy.

As a result of personal experiences, there were potential biases that were important for me to be aware of. In framing my research questions, I sought to be open to unexpected themes and experiences related to sexuality and stigma for survivors. However, my positionality as a survivor may have biased me as I am naturally inclined to assume survivors struggle with issues of stigma and sexuality. Awareness of this assumption allowed me to hopefully manage this bias during the data gathering and analysis process.

My relational experiences coupled with my burn injury have led me to question how other survivors experience sexuality and stigma. More importantly, when aligned with the current research in these areas, it became imperative to find out how survivors talked about and experienced sexuality and stigma with their partners. Therefore, this study was developed to investigate the communication about stigma and sexuality between survivors and their relational partners. Next, the process for collecting data is discussed.

### **Data Collection**

The focus of this study is on the communicative experiences of stigma and sexuality within the survivor/partner interaction. Therefore, it was important to conduct in-depth interviews with both burn survivors and their relational partners. Details of the data collection process such as participants, sampling, recruitment, and the interview process are discussed in detail throughout this section.

### **Participants**

There were 27 participants in the study who participated in an interview as either a burn survivor or survivor's relational partner. Of those interviewed, 19 were survivors, and 8 were partners. In six cases, both the survivor and partner within the same relationship were interviewed. However, the data were analyzed separately. Phenomenological research suggests interviewing 5 to 25 participants that have experienced a given phenomenon (Polkinghorne, 1989). Saturation within a phenomenological study is generally indicated when the researcher feels the essence of the phenomenon has been identified and interpreted (van Manen, 1990). For this study, saturation needed to be achieved for both participant groups, survivors and partners. In

some instances, both relational partners in the same relationship were able to be interviewed, whereas other interviews were conducted with only either the survivor or the partner. According to Creswell (2007), reaching theoretical saturation is more beneficial than a specific number of participants. Therefore, continuing interviews past the point of saturation would not add anything unique to the project. Theoretical saturation may be reached at any number of interviews, depending on the phenomenon under study. As a result, theoretical saturation was reached after 19 survivor interviews while only 8 interviews were needed from partners.

The participants in this study fell into two participants groups: burn survivors and relational partners. Burn survivors were between the ages of 18-68 with an average age of 39. There were 11 female survivors and 8 male survivors. Of the 19 survivors interviewed, 6 indicated they were Black while the other 13 indicated they were White. Two of the survivors indicated they were gay or lesbian, the remaining survivors identified as heterosexual. A large number of survivor participants (n=12) reported being out of the paid workforce by stating they were either unemployed, students, stay at home mothers (SAHM), or retired. Half of the survivors interviewed received their burn injury as a child. Additionally, 7 of the survivors interviewed also received 50% or more total body surface area (TBSA) burned. Table 1 offers an overview of basic demographic characteristics of the burn survivor participants, listing them according to their self-selected pseudonyms.

Table 1

## Profiles of Burn Survivors

<b>Name</b>	<b>Age</b>	<b>Sex</b>	<b>Race</b>	<b>Occupation</b>	<b>Age at Injury</b>	<b>TBSA</b>	<b>Interviewed Partner</b>
<b>Dawn</b>	33	F	White	Financial	29	15%	Jim
<b>Renee</b>	26	F	White	Student	>1, 1	50%	N/A
<b>Smiley</b>	53	M	White	Unemployed	48	41%	N/A
<b>Richard</b>	64	M	White	Entertainment	42	18%	Bette
<b>Elizabeth</b>	29	F	White	Medical	22	15%	N/A
<b>Jennifer</b>	32	F	White	Medical	7	87%	N/A
<b>Riley</b>	24	F	White	Student	5	12.5%	Tank
<b>Anne</b>	38	F	White	SAHM	1	48%	N/A
<b>Jackie</b>	43	F	Black	Medical	6	85%	N/A
<b>Isaac</b>	18	M	White	Student	3	1.75%	N/A
<b>Lucy</b>	38	F	Black	Childcare	38	4%	N/A
<b>Darren</b>	32	M	Black	Unemployed	29	9%	N/A
<b>Amy</b>	27	F	Black	Non Profit	>1	15%	N/A
<b>Nellie</b>	27	F	Black	Unemployed	26	50%	N/A
<b>Poo</b>							
<b>Ralph</b>	53	M	White	Retired	43		N/A
<b>Wu</b>	37	M	White	Unemployed	26	54%	Michelle
<b>Benjamin</b>	63	M	White	Retired	35	30%	N/A
<b>Shannon</b>	34	F	White	Unemployed	12	12%	Jay
<b>Charles</b>	68	M	Black	Retired	9	50%	Avery

The relational partner participants were between the ages of 23 and 69 with an average age of 38. There were four female partners and four male partners. Within the relational partner group, the racial makeup was very diverse: Asian (n=1), Black (n=1), Hispanic (n=2), Middle Eastern (n=1), White (n=3). As with the survivors, two relational partners also identified as gay or lesbian while the remaining partners identified as heterosexual. Occupations within the relational partners' category varied widely with only one person reporting themselves as not engaged in paid work. Six of the partner participants were in a romantic relationship with survivors who were also interviewed for the study. The two remaining partner participants were in a relationship with a survivor

who did not participate in the study. Multiple attempts were made to interview their survivor partners to no avail. Table 2 offers an overview of basic demographic characteristics of the partner participants in the study.

Table 2

## Profiles of Relational Partners

<b>Name</b>	<b>Age</b>	<b>Sex</b>	<b>Race</b>	<b>Occupation</b>	<b>Interviewed Partner</b>	<b>Age at Injury</b>	<b>TBSA</b>
<b>Jim</b>	34	M	Asian	Medical	Dawn	29	15%
<b>Bette</b>	69	F	White	Non Profit	Richard	42	18%
<b>Tank</b>	26	M	Hispanic	Data Entry	Riley	5	12.5%
<b>Claudia</b>	36	F	Hispanic	Admin Asst	N/A		85%
<b>Michelle</b>	30	F	White	Media	Wu	26	54%
<b>Donald</b>	36	M	Black	Childcare	N/A		30%
<b>Jay</b>	23	F	White	Student	Shannon	12	12%
<b>Avery</b>	50	M	Middle Eastern	Education	Charles	9	50%

### Sampling

Participants were recruited through purposeful sampling methods to locate burn survivors and their relational partners. Specifically the sampling strategy used was the criterion technique (Creswell, 2007). The criterion sampling technique allowed for recruitment based on two criteria. First, to be considered a survivor, the participant must have suffered a severe burn injury (i.e., second and third degree burns) requiring skin grafts. Second the survivor must have been released from the hospital for at least six months. The initial plan was to only interview survivors who had been out of the burn unit between six months, but not more than five years. However, this criterion proved to be too limiting to recruit enough participants. The time period was extended to any time beyond six months. This time period allowed for physical recuperation of the actual injury as well as time to experience stigma and sexuality issues. Furthermore, though the



initial plan had been to further limit participation to those whose romantic partners would also consent to an interview, the difficulty in finding such partnerships necessitated dropping it as a criterion from the study.

While many previous studies on sexuality have focused on male survivors (e.g., 70 percent of all burn survivors are male), this study attempted to include the female survivor experience and voice as well. Previous studies have also noted challenges with samples being homogenous in terms of race (Bianchi, 1997). Therefore, additional sampling considerations were taken into account. This study sought equality in recruiting survivors from each gender and beyond a single race. The study was open to all ages over 18. Age was limited to 18 or above as this is the legal age of adulthood and does not require parental consent. Additionally, the subject matter was of a mature nature, and may not be appropriate for those under the age of 18.

### **Recruitment**

Participants were located through local Missouri survivor support groups, Facebook support groups, and Craigslist advertising. As a survivor, the researcher was able to gain entrance to a support group in St. Louis, Missouri and issue invitations (via email and in person) to participate in the study. In addition, Craigslist advertising was posted in major cities across the United States under the volunteer category in an effort to recruit participants. (see Appendix A-C for recruitment scripts)

Another attempted recruitment route was through burn centers and rehabilitation clinics. Preliminary permission had already been granted to recruit survivors from two outpatient clinics in the Midwest. Recruitment was to be done through an employee within the clinics to be compliant with all HIPPA privacy policies. Recruitment flyers

were to be submitted to clinics and then interested participants would be able to contact me personally. Clinics may not give out patient contact information without patient consent. While recruitment in the clinics seemed ideal, these attempts failed to recruit participants, perhaps due to lack of direct access to participants. Clinic workers who did have access to potential participants were not motivated to recruit nor were they able to answer more in-depth questions participants might have about the study should they have inquired.

During the recruitment phase, most potential participants made contact via email. Once a potential participant had made contact to indicate interest in participating in an interview, they would receive a response via email to answer any questions they might have about the study. If they indicated they wanted to proceed with the interview and they were local, a time and location convenient to both parties was negotiated. When the participant arrived at the interview site, they were asked to read and sign a consent form. If the participant was not local, they were asked what platform worked best for them (i.e., phone, skype, Face time, etc.). Most non-local participants chose to do phone interviews. When interviews were conducted via telephone, consent forms were signed online through an application called DocuSign. All consent forms were signed prior to conducting the interviews. After completion of the interview, a request to interview the partner was made as well as any other survivors/partners. While some participants did give me their partners information, only one participant in the study was located through snowball sampling. All participants were offered a \$10 Wal-mart gift card in exchange for participating in the study. Some participants refused the gift cards, stating their

participation was an effort to give back to the burn community. A total of 20 gift cards were given out for this project.

### **Interviews**

Semi-structured in-depth interviews were conducted to collect the data. 27 interviews were conducted, with 19 being survivors and the other 8 consisting of relational partners. To begin the interview process, the nature of the study was discussed. Once confidentiality was assured, the participant was offered a chance to ask any questions.

When possible, interviews were conducted in a place that was comfortable for the participants. Lindlof and Taylor (2002) suggested using a place that provides privacy so conversations may remain confidential and comfortable. Homes of the participants were sometimes used as a site for interviews as it helped participants feel open enough to talk about challenging topics. However, some participants felt more comfortable in public places (such as coffee shops), since they were talking about their relational partner. Seven interviews were conducted in person. The majority of interviews (n = 19) were conducted over the phone, while the remaining interview was conducted via Face time (an iPhone application).

Interviews for survivors and partners opened with general questions about age, family, and then moved to the survivor's burn story (see Appendices D and E for interview protocols). The burn story is often how survivors as well as partners make sense of a traumatic situation (Williams et al., 2003). Next, participants were asked to discuss their stigmatizing and sexual communication experiences after the burn injury based on a series of questions regarding stigma and sexuality. Questions were used as a

guide to elicit information while allowing participants to still tell their story freely without interruption. As participants shared their experiences, conversations were sometimes redirected based on what was learned *in situ*. Questions also shifted slightly from one participant interview to another as the researcher became more familiar with the data and reflected on previous interactions.

Each of the interviews was openly recorded and was 30 to 120 minutes in length with most interviews averaging 60 minutes. Notes were sometimes taken during the interview to track impressions. Interviews were later transcribed by the researcher and a professional transcriptionist, generating a total of 376 transcribed pages of single spaced text. Each transcript was verified by the researcher to ensure the accuracy of the transcription.

The interview process may have been influenced by this researcher's presence in two ways. First, gender may have affected some of the interviews. Some of the men may have felt uncomfortable sharing intimate sexual experiences with a woman, especially when some of these moments may have illustrated their shortcomings. Women may have felt more comfortable relating to a woman as they have experienced similar situations.

Second, direct personal experience as a burn survivor may have impacted how and what many of the participants choose to relate. During initial email communication with participants, the researcher would often disclose her burn survivor status. For example, many of the survivors and partners may have felt a common bond and chose to relate more details because of a perception that the researcher may have understood and strongly empathized with them. However, some of the relational partners may not have

revealed as much, out of fear of being hurtful, since they may have perceived me as a survivor.

Thus, the researcher may have impacted the interview process through her gender and survivor status. The personal status of each researcher impacts the interview process. I acknowledge that my unique personal status may have both positively and negatively impacted the data generation process.

### **Data Analysis**

Phenomenological studies attempt to understand the essential meaning of others' lived experiences (van Manen, 1990). In-depth interviews from burn survivors and their relational partners in which they discuss communicative experiences of sexuality and stigma were examined. This study is phenomenological in that understanding meaning is essential to the goal of the study. To uncover meaning from the interviews, a thematic analysis was conducted for the survivor sample and the partner sample separately. Thematic analysis is "the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (van Manen, 1990, p. 78). Therefore to analyze a particular phenomenon one must locate themes and the structures that guide the experience of said themes (van Manen, 1990, p. 79).

Locating themes is more than counting words; phenomenological themes are "structures of experiences" (van Manen, 1990, p. 79). Van Manen (1990) argued that themes connect to the notion of what is being studied by (a) using theme as a tool to get to the meaning, (b) giving shape to shapeless concepts, (c) describing content of notions, and (d) functioning as a reduction of the notion. The present study uses thematic analysis to get at the notion of the stigma management and sexuality experiences of survivors and

their partners. Survivors' and relational partners' experiences with stigma and sexuality as well as other material and social realities are structures that guide their experiences.

Isolating thematic statements of phenomenon may be done using one of three approaches: (a) a wholistic approach attempts to capture the significance of the text as a whole, (b) a selective approach goes through texts several times looking for particular phrases that appear revealing or essential, and (c) a detailed approach asks what each sentence reveals about the experience (van Manen, 1990). This project used the selective approach to locate the most relevant parts of the interview to focus the analysis on stigma management and sexuality.

The first step in analyzing the data was to read all of the transcripts through entirely multiple times. Next, the researcher engaged in selective reading. Selective reading involves reading through specific parts of a text several times to locate statements or phrases that reveal the phenomenon (van Manen, 1990). At this point the researcher went through each of the texts paragraph by paragraph and coded portions of the data relevant to the participants' experiences with stigma and sexuality. With the assistance of Atlas.ti, qualitative analysis software, the author used open and axial coding to code passages (Strauss & Corbin, 1998). The researcher focused on comparing experiences across participants and coded common incidents, adapting, combining and adding new categories based on the data.

### **Analyzing Stigma Strategy Use**

As noted above, the phenomenological analysis process began by first closely reading each of the interviews. Then the moments of stigmatizing interactions were identified and coded as an appropriate strategy. Whenever strategies fit Meisenbach's

(2010) SMC model, those category names were used. After each interview and stigmatizing moment was coded, analysis indicated that the strategies all easily collapsed into five larger categories noted in the SMC model (Accepting, Avoiding, Reducing Offensiveness, Denial, Ignoring/Displaying). No stigma management codes fell outside of these pre-existing categories. At this point, as a process akin to axial coding, a table was created that listed each of the larger categories across the top and the names of the participants down the side (see Table 3). A review of the codes within each transcript allowed the researcher to visualize what strategies were articulated and experienced by each participant. Upon review of the completed table, patterns began to appear. Participants were then rearranged into groups based upon common patterns of strategy usage.

Table 3

## Survivor Stigma Strategies

Name	Accepting	Avoiding	Reducing Offensiveness	Denial	Ignoring/Displaying
Dawn	X	X	X	X	X
Renee	X	X	X	X	X
Smiley	X		X		
Richard			X	X	X
Elizabeth			X	X	X
Jennifer	X	X	X		
Riley	X	X	X	X	X
Anne		X	X	X	X
Jackie	X	X	X	X	X
Isaac			X	X	X
Lucy		X	X	X	X
Darren	X	X	X		
Amy		X	X	X	X
Nellie Poo		X	X	X	X
Ralph			X	X	X
Wu			X	X	X
Benjamin		X	X	X	X
Shannon		X	X	X	X

Charles	X	X	X	X	X
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### **Analyzing Sexuality**

The second research question explored in the results chapter pertains to the sexuality of burn survivors. Survivors and their partners constructed sexuality in four ways. This result was found by first identifying all passages within transcripts that discussed sexuality. These passages were copied and pasted into a document and rearranged until clear themes and patterns of construction began to emerge. At first there were only three categories: feeling not sexy, being fragile, and being anew normal. However, as the researcher moved forward in the writing process, the fourth category of sexuality not being impacted became important to note. As sexuality was constructed by survivors and their partners, the meaning of sexuality should be apparent within the phenomenological analysis. Although the analyses of partners and survivors were conducted separately, results for the second research question are presented in combination due to the overlap in themes among the survivor and partner samples.

### **Validation strategies**

Validation of one's research is "an attempt to assess the 'accuracy' of the findings" (Creswell, 2007, p. 206). Creswell recommend that qualitative researchers engage in at least two validation strategies for each study. This study will employ two validation strategies; rich thick description and clarifying researcher bias.

Throughout the research process, giving participants voice is central to the interpretive paradigm (Creswell, 2007) as well the project as a whole. Specifically, the use of rich thick description was used to characterize participants' voices and experiences. The interpretive approach is also very reflexive and allows for a more



literary writing style to engage readers (Creswell, 2007). Therefore detailed descriptions of participants' experiences and direct quotes were used throughout the analysis.

As previously discussed, the researcher has close ties to the nature of the study. Therefore clarifying researcher bias will assist the reader to understand the potential biases that have shaped the approach and interpretation of the project. As noted in the researcher's standpoint section of the chapter, past experiences of the researcher were shared that may potentially impact the direction of the study. Additionally, researcher bias was kept in mind throughout the writing process through the process of bracketing.

### **Summary**

In sum, this section discussed the assumptions of the interpretive paradigm, explained the hermeneutic phenomenological methodology, detailed the researcher's standpoint, and outlined the data collection and analysis process. The goal of this study is focused on exploring the stigma and sexual experiences of survivors and their relational partners. A phenomenological approach supports this goal in that meanings may be explored in the lived experiences of survivors and their partners.

## **CHAPTER 4: RESULTS**

The goal of this chapter is to present the results of the phenomenological analysis of burn survivors' and relational partners' stigmatizing and sexuality experiences.

Survivors and partners were asked during semi-structured interviews to talk about their experiences with sexuality and stigmatizing communication post-burn. Analysis of the interviews indicated clear patterns of stigma management and differing constructions of sexuality. The results are presented in relationship to each research question, beginning with a focus on stigma communication.

### **RQ1: Stigma Management**

Research question one asked how stigmas were reflected in/managed by burn survivors and their romantic partners. Both burn survivors and partners in this study showed specific patterns of stigma management strategy usage. However, survivors showed more variation in strategy selection than partners did. Four clear patterns of stigma strategy usage emerged from the survivors. Within some of the usage patterns, strategies were described as shifting as the survivor gained experience with their scars while other patterns indicated little change with time. While burn survivors showed a variety of stigma management strategy use, the romantic partners of survivors stuck to one clear category of strategies. Specifically, partners indicated a strong denial pattern, working to deny or challenge stigma messages relating to their survivor partners' burn scars. Since survivors and partners had such a different approach to strategy selection, each group is discussed separately, beginning with the survivors.

## **Survivor Strategy Use**

When considering how someone manages a stigma, the findings suggest the need to account for the process of shifting among strategies. Many survivors are engaged in a process of perceiving their new bodies and recognizing the applicability and existence of a burn stigma for the first time as a result of the injury. These interviews revealed that as survivors adjust to their bodies and others' reactions to it, their management of stigmatizing messages varies. Furthermore, the process of shifting strategies for survivors is not the same for everyone.

The current findings showed how burn survivors shifting among stigma management strategies did so in four patterns as: Accepters, Situational Adopters, Challengers, and Dissembling Challengers. The Accepters pattern indicated that survivors continually alternate among three strategy categories: avoiding, accepting, and reducing offensiveness. In this pattern, the survivor never discussed trying to challenge public stigmatization of their burn status. Second, the Situational Adopters pattern indicated that survivors used five categories of strategies to manage stigma. These survivors shifted among avoiding, accepting, denial, ignoring/displaying, and reducing offensiveness strategies. The Challengers pattern showed survivors using three categories of the SMC model, only one of which overlapped with the three pronged accepters strategy. This pattern established that survivors primarily used the denial and ignoring/displaying strategies to challenge public understanding of stigma and applicability to self while still incorporating the strategy of reducing offensiveness. Finally, survivors falling into the Dissembling Challengers pattern described using four strategies. The name Dissembling Challengers was chosen as survivors within this

pattern not only challenged others' perceptions of stigma but also engaged in strategies that attempted to conceal the scars. Survivors within the Dissembling Challengers pattern managed stigma by continually shifting among the avoiding, reducing offensiveness, denial, and displaying/ignoring strategies. Table three offers an overview of the strategy types found in each pattern.

Table 3

## Survivor Stigma Management Patterns

<b>Accepters</b>	<b>Challengers</b>
Accepting	Denial
Avoiding	Ignoring/Displaying
Reducing Offensiveness	Reducing Offensiveness
<b>Dissembling Challengers</b>	<b>Situational Adopters</b>
Avoiding	Accepting
Denial	Avoiding
Ignoring/Displaying	Denial
Reducing Offensiveness	Ignoring/Displaying
	Reducing Offensiveness

***Accepters pattern.*** The first pattern, Accepters, showed that survivors within this category continuously shifted among three SMC strategies: Accepting, Avoiding, and Reducing Offensiveness. Accepters' strategy usage seemed to be continuous across their lifetime and often depended on a given situation or relationship in which the survivor was interacting. Interestingly, survivors in the Accepters pattern did not use the denial or ignoring/displaying strategies. These survivors only challenged others' perceptions by engaging in the reducing offensiveness strategy. All of the other strategies they chose are associated with accepting others' perceptions of the stigma. In the sections below, examples of the survivors describing their use of each strategy are offered.

***Accepting.*** Within the Acceptor pattern, humor eased the interactions between stigmatized and non-stigmatized individuals. Using humor was the only sub-strategy of

the accepting strategies that this group typically used. Smiley is a 53 year-old White male survivor who was burned six years ago as a result of electrical burns on the job and has 41% of his total body surface area (TBSA) burned, including a highly visible facial burn. He is currently married with adult step-children and unemployed due to disability from his burn injury. Smiley said, "I try to keep a sense of humor." He often told jokes about his scars to relieve the tension for non-stigmatized others. He repeated a joke during the interview that he had heard a comedian tell about a burn survivor being "burned beyond recognition... But don't you think it's more he's burned to recognition? You know? Because you can pick him right out of a crowd. Yeah, it's true!" Smiley acknowledged that he likes to tell this joke to others.

Smiley also used the accepting strategy in situations in which people stared at him. Specifically, he recalled experiences with children and their parents:

Little kids stare. You know, and then their parents get embarrassed. They don't, they don't know what to do. They're like, "uh". Uh. Most of the time, I'll just say, "Ah, don't play with fire" or something, you know, just kinda joke around.  
[Smiles & Guffaws]

When Smiley joked around, he was attempting to diffuse an awkward situation. This attempt at humor demonstrated an acceptance sub-strategy.

Using humor was also a useful strategy for Jennifer. Jennifer is a 32 year-old White female survivor who was burned at the age of seven as the result of a motor vehicle accident and has 87% of her TBSA burned (most of her body is scarred). She is currently married with children and working in a NICU. Jennifer used the accepting strategy, specifically in the form of using humor to ease comfort at work in the NICU where she is often faced with new parents' questions about breastfeeding. As Jennifer was unable to breastfeed her own children due to lack of breast tissue from scarring, she

often engaged parents using humor. When talking about a lactation consultant to a patient, Jennifer jokingly said, “If I had nipples, I would let [the consultant] help me lactate.” So Jennifer was very open with parents in that situation not only about having burn scars but also about the double stigma of not being able to breastfeed her children in her work environment, especially when the breastfeeding information would be beneficial to concerned new parents. In some ways she may have been inviting the patients to stigmatize her burn survivor status as a way to see their own inability to breastfeed as less stigmatizing. However, it is worth noting that her use of humor might also work to actually challenge the patient’s idea that Jennifer’s burn survivor status is anything that should be stigmatized.

*Avoiding.* Avoiding is a strategy that survivors in the Accepters pattern used to hide their burn scars. While Jennifer had described using an acceptance strategy when talking to patients, in other situations she has chosen to respond by using an avoiding strategy. For example, in intimate moments with her partner, Jennifer noted, “And even today, I still don't... really want to be like totally undressed.” She was uncomfortable completely revealing her marked body to her husband so she preferred to hide herself as much as possible with clothing. While Jennifer’s scars cannot be completely concealed, clothing did offer her some sense of a barrier. Even when her partner offered assurances of her beauty, she said “I really have a hard time believing him.” Therefore, engaging in an avoiding strategy was Jennifer’s way of managing stigma when her self-confidence was challenged by her partner potentially viewing her stigmatized body.

Darren used the avoiding strategy in specific situations as well. Darren is a 32 year-old Black male survivor who was burned in an automobile fire approximately 3

years prior to his interview. His burns cover both hands and forearms. Darren is currently single and unemployed due to his burn injury. Darren often worried how he would be perceived by potential dates. Therefore, he attempted to hide his scars as much as possible: “Sometimes I hide it. I'll wear a jacket or a long-sleeve shirt.” Darren admitted that engaging in this strategy was a strategy choice that he used more often as he was getting used to his body and others’ perceptions of it. When asked how he explained his scars to those he dated, he replied:

Darren: Um. I just put it out there and let them know it. If they like it, they like it. If they don't, they don't, I'll just move on. You know, I just learned to deal with it.

Interviewer: OK. What do you mean you learned to deal with it?

Darren: Because at first, I was nervous to date, or I was nervous to tell anyone that, what was going on. I just tried to hide it. And so that, you know, if you like me, you like me for me.

This exchange indicated that Darren was fully aware of others’ potentially negative reactions to his scars. So while his initial strategy was to avoid disclosing and hide the scarring, he had to tell his partners at some point. In revealing his burn scars to dating partners, Darren was taking a chance on whether his partner would accept or reject him. Darren currently has a partner of three months, therefore, it is unclear if he would return to the hiding strategy if he were to resume dating.

While Smiley did not engage in the avoiding strategy, I suspect it was because he was unable to hide his facial scars in particular. When discussing how his face looks he replied, “The only time I really have a problem with it is if I stand and look in the mirror too long.” It seemed that standing in front of the mirror and looking at his scars caused Smiley some amount of distress. Therefore, based on this response, I suspect that if Smiley was able to hide his scars he would do so.

*Reducing offensiveness.* The last strategy used in the Accepters pattern was reducing offensiveness. Bolstering/refocusing was one sub-strategy for reducing offensiveness that was discussed frequently by burn survivors. Refocusing involved shifting the focus from the survivors' stigmatized identity to the non-stigmatized aspects (Asforth & Kreiner, 1999). For example, Jennifer highlighted her ability "to stay focused on something greater than just my body and just my skin, that I can focus on what my heart has to give and, you know, what my heart can receive from other people." This quote showed how Jennifer shifted the focus away from her scars and focused on her ability to interact with others in a meaningful way.

Jennifer also talked about coming to terms with her injury, which correlated with the transcendence sub-strategy. Transcendence reduces the offensiveness of the stigma by focusing on positive outcomes from the stigmatizing experience (Meisenbach, 2010). For example, Jennifer suggested that once she was able to see her scars from a different perspective she was able to find value in her life:

When I finally was able to see that it was so unique and that it really was a miracle that I lived, and I could see how um it set me apart in a good way, then I was able to share it [my burn story] um with more confidence and more esteem than being ashamed.

Finding value in her life and reiterating the uniqueness when retelling her story to others challenged their perceptions of stigma.

Smiley also used the reducing offensiveness strategy to manage stigma, specifically the minimization sub-strategy. Minimization works to reduce the offensiveness of the stigma by showing how it does not harm others (Meisenbach, 2010). Smiley engaged in this strategy during the interview when discussing his responses to others staring at him.



The thing that bothers me is the people that um, you know, you'll be walking down the road, and you see them looking at you. And then when you get up to them, they divert their eyes instead of just saying, "Hey, how are you doing?" Or, you know, just saying hi. Don't avert your eyes once I get to you. I mean, you know, it's not like, it's not like you're going to catch something, you know?

By suggesting that people will not “catch something,” Smiley minimized the perceived offensiveness of his scarring, thus challenging others’ perceptions about how bad the stigma characteristic is. Each of these survivors has typified the Accepters pattern of shifting among stigma strategies as they continually use the accepting, avoiding, and reducing offensiveness strategies as needed in their daily life.

*Situational adopters pattern.* The Situational Adopters pattern of stigma strategy use is explained as using five of the six SMC stigma management strategies: accepting, avoiding, denial, ignoring/displaying, and reducing offensiveness strategy. While shifting across a large number of strategies may appear random, the findings suggest that strategy selection is situationally as well as relationally dependent. The sections below provide examples of survivors shifting among stigma strategies from the categories discussed above.

*Accepting.* During the early injury phases, accepting was a common strategy used by situational adopters. Isolating the self was a discursive sub-strategy of accepting as it allows the survivor to limit communication with others. Charles is a 68 year-old Black male survivor who was burned when he was 9 years old in a house fire and has 50% TBSA (scars covering arms and torso). He is currently in a long-term same sex partnership and retired. Charles spoke of how other children would taunt him with chants like “Burner, burner, blacker, faster.” In response, he chose to isolate himself from others, “I just stayed in the house and stayed, stayed away from the other kids... and didn’t go anywhere.” By staying in the house, Charles demonstrated the acceptance

strategy to manage his stigma as a response to stigmatizing teasing messages from his peers.

Jackie also found the isolating sub-strategy useful early in her injury. Jackie is a 43 year-old Black female survivor who was burned when she was 5 years old in a scalding accident and has 85% TBSA (scars cover most of her body). She is currently in a new relationship and working in hospital administration. Jackie recalled, “When it was time to go to school, I remember crying, saying I didn’t want to go to school because everybody was gonna know, you know, about my burns.” Jackie wanted to isolate herself because she feared others’ reactions to her scars. While Jackie’s use of the isolation sub-strategy is similar in nature to Charles’, her use was more preemptive rather than responsive like Charles’s strategy use.

While isolation from society offers some protection from non-stigmatized others, bonding with stigmatized others was another sub-strategy of accepting practiced by these survivors. Bonding with stigmatized others offered a method of coping for the survivor as well other survivors in a peer support environment. Renee found ways to relate to other survivors. Renee is a 26 year-old White female survivor who was burned twice, once as an infant then again as a one year-old. Both incidents were a result of scalding due to child abuse that left Renee with 50% TBSA (scars involve the feet, legs, back, and upper arms). She is currently married with children and a stay at home mother. Renee found herself drawn to work in a burn unit in previous years: “I felt like, of all people in the burn unit, I can relate to these people. And I thought that it would be helpful for them to have someone caring for them that had been through it.” By working in the burn unit, she was able to offer some peer support to others while also feeling like she was

connected to a group that was much like herself, thus demonstrating the bonding with stigmatized others sub-strategy.

*Avoiding.* When an individual accepts the existence of a public stigmatization of a characteristic but tries to deny the applicability of that characteristic and stigma to oneself, they engage in avoiding strategies (Meisenbach, 2010). Renee found the avoiding strategy to be a helpful way to deal with hiding her scars. While she wished to be able to wear the latest styles as a teen, she avoided some particular items that were more revealing: “I almost never wore sho- shorts growing up, 'cause I'm not comfortable wearing really short shorts that partly just--well, I just didn't want to fight with it.” It was easier to avoid showing her scars than to build confidence to display them and have to deal with questions or concerning stares.

As Jackie was also burned as a child, she also found the avoiding strategy to be useful in her youth. When talking about her experiences as a child, she said “grade school, it was pretty much the same, you know, always wearing long pants, always wearing long socks. Umm, never wanting to be exposed.” So Jackie attempted to cover up her scars to prevent exposing them to others. Jackie’s use of the avoiding strategy could be interpreted not only that she accepts others’ perceptions that burn scars are stigmatizing but also as her way of challenging that the stigma from the burn scars applies to herself.

*Denial and ignoring/displaying.* When an individual not only denies the applicability of stigma to self but also challenges the public understanding of that characteristic as stigmatizing, they may engage in a denial strategy. Denials may be very simple and straightforward and declare there is no stigma. In other cases, the person may

offer an argument for why they should not be stigmatized. Such was the case when Renee discussed how the survivor's body changes after the burn and the struggle to accept their new look. She claimed that "It doesn't matter what you look like." Renee's comment is an example of a logical denial. The hidden premise is that you only struggle over and stigmatize things that matter. Since Renee has argued that what you look like doesn't matter, one can infer that Renee doesn't struggle to accept the way she looks and should not be stigmatized.

Another form of denial is to ignore or display the stigmatizing mark in an effort to deny the existence of a stigma. An earlier example of Renee showed that she sometimes would hide her scars, however, she did choose to wear a bathing suit to go swimming throughout her youth, thus sometimes engaging the ignoring/displaying strategy. And while Renee would "deal with the looks and the pointing and the whispers" that she would receive, she "was really good at faking confidence." In this instance, Renee chose to display her scars and fake confidence because she really wanted to go swimming. However, in the previous situation of choosing to wear shorts, there was no clear reward, or at least not one that could summon confidence that she required to make the display. While Renee displayed confidence in the swimming instance, she "did not feel confident at all." Renee's choices to hide or display her scars demonstrated that situational context may explicitly influence choice of strategy.

Dawn also demonstrated the use of the ignoring/displaying strategy. Dawn is a 33 year-old White female survivor who was burned four years ago in a fire accident and has 15% TBSA (scars on back, buttocks, and back of thighs). She is currently married and working in financial services. Dawn chose to post graphic photographs of her injuries on

Facebook. While Dawn initially didn't perceive the stigmatizing nature of her burn injury, she quickly realized the stigmatizing effects to self and others' perceptions based on the comments she received. In fact, Dawn noted that:

I ended up putting pictures up on Facebook, which I have friends on Facebook that work with me, and so I think that also perpetuated some of the issues. So I think advice for others, like be, just be cautious and careful in how you represent what had happened to you. People are interested and curious, only allow those people in, but knowing that if you strut it to the world and all of your friends on Facebook, it's out there for the world to see, and people are going to jump to conclusions. It's only natural. Uh. So I think that was one thing I could look back and say, "Hmm, that probably wasn't the smartest decision," but at the same time though, a lot of people asked me, you know, "How are you doing? I'd like to know what's going on," or whatever. Again, I have a lot of friends from college who are out of state, and so they were curious, they were worried. Uh. And yeah, it's easy just to be like "Oh, here are all the pictures," versus emailing one picture at a time. So it was just easier to do it that way. So from my mindset it was, "Oh, well, this is just the people that want to see it. Like they'll go, they'll look, whatever." But it was like no, that's not at all what happened, so.

Because she posted the photographs, a challenge developed in Dawn's workplace that resulted in negative stigmatization.

So, there was this one gentleman that I worked with who was indirect leader or an indirect boss for one of the products that I was working on. Umm, and so, I had issues with him before like him saying inappropriate things and he had called me to the conference room and I was trying to get to leadership at the time, umm he had said you know one of the things that is holding you back is because of the decisions you make. And I said what do you mean? And he said the fact that you got burned and basically lit yourself on fire, I'm like a) you don't know the whole story and like b) that's something that is very personal and the fact that that would be held against me is kind of ridiculous and I felt that was very inappropriate to even think that way. And he was like no, like people just think that you make rash decisions and he just went on and on and just tore me down.

This incident supported a challenge to a co-worker's perceptions of Dawn as stigmatized.

While Dawn initially was not aware of stigmatization of burn scars, her display still challenged others' perceptions. The later encounter with a co-worker then emboldened her to challenge his perceptions, thus denying the existence of the stigma. .

*Reducing offensiveness.* Transcendence as a sub-strategy is a way of reducing offensiveness. Within the Situational Adopters pattern, the use of the transcendence sub-strategy was a turning point for survivors to recognize the more positive aspects that have come out of their stigmatizing experiences. For example, Renee said that:

my scars have made me into who I am. And especially my ability to empathize I think comes from the fact that... I've had the experiences that I've had. And I wouldn't change that, even if it means keeping my scars.

This quote typified the transcendence experience of survivors by showing how Renee focused attention on a positive quality (empathy) that resulted from her experiences as a survivor. In this instance, Renee's experience as a survivor enabled her use of the transcendence sub-strategy.

Similarly, other survivors like Dawn not only incorporated the stigma into their identity but also suggested that the burn helped them acquire new-found attributes such as strength, compassion, and empathy from their experience.

I think I look at it [my burn injury] as it made me who I am today. It made me a stronger person and I think it's given me a lot more compassion towards other people... I feel like I can relate. I can truly empathize with the situation that their going through.

Charles echoed these notions, saying his experiences "made me respect others... And it made me stronger." Survivors using this Situational Adopters pattern continued to see the positive aspects of their burn experience and wished to share it with others. In fact, Jackie said,

You know what, as ironic as it sounds, I think I wouldn't, I don't think I would be the same way and I think the injury, that's why I say in this, I count it as a blessing, you know, when I was younger I didn't think that, but I really, really count it as a blessing, looking on the other side, you know, and I do, you know, like I said, I have a strong faith that you know, and when I'm witnessing to people, I share my story with them. Umm, you know, that, you know we go through a lot of things in life, you know, life throws us a curve ball sometimes we're not even prepared for. And I've had my share of struggles.

So here, Jackie indicated that not only had she found the positive aspects of her scarring and injury, but also felt it important to share her struggles with others.

Each of these survivors has typified the Situational Adopters pattern of shifting among each of the five stigma strategies as dictated by their situation and relationship needs. The Situational Adopters pattern is set apart from the Accepters pattern as the Accepters do not use denial and ignoring/displaying strategies. Survivors within the Situational Adopters pattern shifted among all the stigma management strategies.

*Challengers pattern.* Third, there is a Challengers pattern to shifting within the stigma management strategies. This pattern has very subtle shifting in that the shifting only occurs among the reducing offensiveness, denial, and ignoring/displaying categories. All of these strategies involved challenging public opinions about the burn stigma. What is significant about the survivors that fall within the Challengers pattern is that they do not discuss engaging in avoiding strategies such as hiding their scars or accepting strategies such as isolating themselves. Those within this category never talked about accepting the public understanding of stigma like the Accepters or Situational Adopters; rather they only shared examples of challenging others' perceptions. Furthermore, the only times these survivors accepted that stigma applied to themselves was when engaging in the reducing offensiveness strategy, often specifically the sub-strategy of transcendence. The sub-sections below provide examples of the survivors detailing their use of these stigma strategies.

*Ignoring/displaying.* The ignoring/Displaying strategy was one strategy Challengers used to challenge others' perceptions of stigma. Richard's experiences were highly representative of the Challengers approach. Richard is a 64 year-old White male

survivor who was burned 22 years ago in an automobile explosion and has 18% TBSA (scarring on the face, thighs, chest, hands, groin). Currently he is married with adult children and works in the entertainment industry. As a youngster, Richard's sibling had cerebral palsy leaving him "heavily handicapped" and exposing Richard to significant unwanted staring, a courtesy stigma: "I grew up with people staring and wheelchairs and that. I grew up with that. It was pretty common." When Richard received his own burn injury as an adult, he perhaps was already equipped to manage at least some of the stigmatization of the scarring because the staring was already so commonplace for him. Despite the fact that his scarring was a highly visible facial burn, he said, "I've never really had a difficult time with it." Furthermore, he noted that "in ways, that relieves me of the burden--that I'm not hiding. It's much more liberating to [say] "Here it is." I have no way of hiding it other than wearing a paper bag around, over my head. So let's move forward." The fact that Richard was not even able to hide the scarring allowed him a freedom to display and reject the stigmatization. In fact, as Richard was leaving the hospital, his face was entirely wrapped up in bandages with only slits cut for his eyes, nose and mouth. Yet, when his partner asked if he wanted to go shopping for a few necessities, "I said, "Sure, let's go." She says, "You sure you're OK?" My comment is, "I'm still the same person inside. And it's everybody else's problem. If they want to stare or look, what difference does it make?" Therefore, Richard's display actively challenged the public perception of stigma as well as applicability to self. He didn't let others' perceptions of his scars influence his sense of self.

Elizabeth also typified the Challengers pattern when she used the displaying strategy. Elizabeth is a 29 year-old White female survivor who was burned six years ago



in a bonfire and has 20% TBSA (scarring on legs). She is currently engaged to be married and works in the medical field. When speaking to Elizabeth about changes in her sexual experiences, she had the following to share.

Elizabeth: I think, I think it changed m- my sexuality emotionally.

Interviewer: How's that?

Elizabeth: But I think it made my sexuality more mature, like made me a more mature partner.

Interviewer: OK. Can you tell me more what you mean?

Elizabeth: Um. I guess like I didn't have anything to hide or hold back, so I'm more vulnerable, so I'm more willing to say things or do things or um just be intimate with a person in general. I'm just more apt to opening myself up to that person.

Interviewer: OK. And you think that was because of the burn or because of the scars?

Elizabeth: Yeah. I think it, I think it wasn't necessarily like due to my scars but just the whole experience and realizing um that I didn't really care as much of what other people think. I guess it had to do with that somewhat.

Elizabeth talked about her whole experience with the burn injury altering her response to a partner seeing her in a sexual situation. She talked about her vulnerabilities (i.e., the burn scars) being external, therefore, it became easier to enact a displaying strategy that highlighted her notions of challenging the applicability of stigma to self and others' understandings. Ignoring/displaying was one strategy that Challengers used to manage stigma. The next section details the other way in Challengers manage stigma through denial strategies.

*Denial.* Denying the applicability of stigma to oneself and challenging others' opinions may appear in the form of simple or logical denial strategies among those enacting the challengers pattern of stigma management. A simple denial, as previously

discussed, may directly refute the existence of stigma. Logical denials on the other hand, involved work on the part of the stigmatized to deny the existence of a stigma through argumentation strategies. One type of logical denial was to attack the accuser. This sub-strategy was illustrated in Wu's response to others staring at him. Wu is a 37 year-old White male who was burned 12 years ago when his hair was accidentally lit on fire. He has 54% TBSA with most of his scars appearing on his face, neck, chest, arms, and back. Wu is currently in a relationship and unemployed. He stated that "I just feel like they're [those who stare at me] kinda weak. 'Cause they can't um, they can't come out and confront like our own mortality." By condemning the non-stigmatized for their weakness he challenged the validity of his own stigma as well as others viewing him as being stigmatized.

Other logical denials focused on refuting perceptions of stigmatization by educating others. Richard has an extensive facial burn and was often confronted with unwanted staring. Rather than quietly feel and accept discomfort with the staring, Richard chose to engage with the non-stigmatized others in an attempt to re-educate:

I see them staring, I'll talk to them about it and invite them to sit down, and we'll talk about it... I can make it mean something to somebody else, and they can move forward and make it good for somebody else--turn it into a safety message, turn it into a[n] awakening for somebody. And then they then expand their mind a little bit.

For Richard, the scars were not stigmatizing to himself nor should they be to others.

*Reducing offensiveness.* Like in all of the patterns, survivors in the Challengers pattern also engaged in the reducing offensiveness strategy. Challengers using this strategy recognized that the stigma applied to them while attempting to change how others perceive it. Richard used his recovery time at home to reflect upon his life as he used the transcendence strategy.

It was a, it was a time to reflect. I was 42 years old. It was time to look back at what I had done. And I was successful and I had nothing to apologize for, but I was focused on who had the most boats at the lake house and all these other material things in life. And the humbling experience of going through a burn and all the problems that it brought with it, and knowing that I'd done it to myself, it was a great opportunity to say, "Let me take stock of myself and see what mark am I going to leave in life." You know, when they rolled me feet first into the uh ER room, the nurses weren't asking the paramedics how many boats he had at his Lake house. That didn't make a damn bit of difference. And it kinda, you know, made me think about what's really important in life. And to have somebody that stood with me--didn't have to. She could have walked away, said, "The hell with this. This is more than I can handle," but she didn't. Um. That's a big life lesson.

During the recovery time, Richard attempted to find a higher meaning or lesson to learn from his injury to move forward. Rather than waste time focusing on other aspects of negotiating stigma, he moved straight towards the transcendence strategy. While Richard actually wore his scars on his face, he spent some time talking about how his injury allowed him to focus on important aspects and really changed the direction he was headed for the better.

It was the worst day of my life, but in many ways it was the best day of my life. I wasn't a dysfunctional shit-bum, but I drank every day. And when I look back on it, it wasn't a good time. It was problem-laden, but it gave me the opportunity to really straighten a lot of things out and look back and reflect on it and open my life to a bunch of good things. And I had a better life my second half of my life than I probably had in the first half.

So in this example, Richard explained how his life was changed for the better by his injury. He wasn't forced to reevaluate his life; the injury just provided the opportunity for reflection. Upon that reflection, Richard was able to perceive his injury in a positive manner, thus reducing the offensiveness of it. While this reflection may reduce the offensiveness of the stigma, it is not clear that this reflection is a response to a stigma message. Therefore, how this type of reflection may be used by survivors is explored in chapter five.

In a similar instance, Wu also talked about his transcendence experience. When discussing why he and his partner Michelle were together, Wu made the following remarks.

Wu: Being burned uh humbles you.

Interviewer: How so?

Wu: Well, when you [get burned] um when you have to fight for your life, it makes you appreciate things a lot more. At least it did-- At least it did for me. I'm not trying to put any words in anybody's mouth or anything. But for me, um I've become a much better person because of it. So I think like before I got burned, I would, I would have been much too cocky. I'm still cocky, don't get me wrong. But I'm much different.

While Wu's experience may not have been as life changing as Richard's experience, Wu did express his newly found appreciation for things and spoke to a small amount of humbleness or at least reduced cockiness. His statement indicated an acknowledgment that he has become a better person due to the injury, thereby reducing the offensiveness of the stigmatizing injury. By thinking in this way, Wu reduces his own perception of the offensiveness of the stigma.

Each of these survivors has typified the Challengers pattern of shifting among the ignoring/displaying, denying, and reducing offensiveness stigma strategies. These survivors all chose to challenge others' stigmatizing perceptions of burn scars no matter the situation or relational implications. The only time this group of survivors acknowledges the applicability of stigma to themselves is through the use of the reducing offensiveness strategy.

***Dissembling challengers pattern.*** The final pattern, Dissembling Challengers, indicated that survivors shifted among the Avoiding, Reducing Offensiveness, Denial, and Ignoring/Displaying strategies. Survivors within this category did not discuss using

the accepting strategies that Accepters and Situational Adopters used, only sometimes potentially accepting the public's opinion of stigma when trying to hide their scars (an avoiding strategy). Interestingly, all of the survivors who fit this pattern were women. The remaining sub-sections provide examples of the survivors detailing their use of these stigma strategies.

*Avoiding.* One method of avoiding stigmatization is to hide the stigmatized attribute. This was a very common strategy for burn survivors who had the ability to hide their scars. Anne admitted that she would sometimes engage in hiding her scars in certain situations. Anne is a 38 year-old White female survivor who was scalded when she was 22 months old with 48% TBSA (scars on the left side of body from top of head to waist). She is currently married and a stay at home mother. Anne said:

if I would want to go somewhere, and I don't want anybody to see it, I c-, I camouflage all of it. I, just by parting my hair a certain way, it all covers it. So uh all through high school, I did not-- Nobody knew.

The ability to hide her scars helped Anne engage with others as a normal rather than stigmatized other.

Survivors often go to great lengths to cover or hide their scars from others. In fact, Amy suffered through additional clothing in the summer to hide her scars. Amy is a 27 year-old Black female survivor who was scalded at 10 months old with 15% TBSA (scars cover her collar bone, back, and right arm). Amy is currently single and works in the non-profit sector. She demonstrated using the avoiding strategy, saying that “in the summer, I wear a long sleeve shirt, of course, so you can't see it.”

Others survivors such as Lucy, talked about how they used the avoiding strategy presently but think that eventually this strategy's use will dissipate. Lucy is a 38 year-old Black female survivor who was burned in a fire 6 months prior to her interview, receiving

4% TBSA (scars on her leg). She is currently single and works in the childcare industry. When asked about the visibility of her scarring Lucy said, "I really don't wear sh- um shorts. I kinda wear jeans. Maybe when next summer comes around, summer comes around. I'll let it show." Here Lucy indicated that she is currently engaging in the avoiding strategy but acknowledged that this strategy choice may change in the future. Therefore, engaging in the avoiding strategy for some survivors is only a temporary strategy choice and one that may be abandoned after the survivor gains experience with the stigma condition. When Lucy was asked how others might perceive her scars, she responded,

I don't think it'll be a problem. 'Cause I mean I've seen people that have burns on their face, and she goes around like she's a carefree person and she don't care if somebody looking at me as an ugly person or--getting burned I don't think makes you ugly. It's just, it's just a part of life--it's just something that happened. So they can look at it and stare some people are going to look at you and stare and go "Oh, so you got burned?" or "What's going on?" It just seems like they're going to look at you.

So Lucy acknowledged that she was aware that others may stare at her scars when they are revealed, however her previous statements indicated that she may not be ready to face those moments just yet. Therefore, engaging in the avoiding strategy at this time indicated her acceptance of others' perceptions of stigma. When she is ready to reveal her stigma and move forward into the ignoring/displaying strategy as she predicted in her earlier quote, then Lucy might begin challenging others' perceptions of stigma.

*Ignoring/displaying.* Survivors in the Dissembling Challengers pattern often described using the ignoring/displaying strategy in stigmatizing encounters. Amy, who was previously mentioned as using an avoiding strategy, spoke about covering up her burn scars. However, Amy didn't always cover up, sometimes in the summer she went to

the beach and wore a swimming suit, thus engaging the ignoring/displaying strategy.

When asked how she handled others who might stare at her scars, she replied,

Amy: Um. A few people have just said, "Oh, my gosh." Like "What happened?" I don't really notice anyone staring.

Interviewer: OK. What do you tell people when they ask you what happened?

Amy: Um. Tell them I got burned when I was a baby.

Interviewer: OK. And most people are satisfied with that?

Amy: Yeah, they don't really ask any more questions.

Interviewer: OK. How does it affect you when people ask? Does it bother you?

Amy: I'm so used to it, I've had it all my life, so it doesn't really bother me that much.

In this instance, Amy used the ignoring/displaying strategy. She displayed her scars by wearing a swimming suit to the beach, and suggested that the stares did not impact her. Clearly the beach situation dictated a specific type of clothing, and Amy found herself adjusting her strategy to the contextual situation at hand.

Previously Anne described using an avoiding strategy, however, in another instance, Anne described a moment with her partner in which she used the displaying strategy.

Where we sit in the living room, you know, his chair and then my chair. And, you know, if he looks across at me, he's looking at my bad side... [he's] seeing all the parts that I usually don't let people see.

Therefore, she revealed her stigmatized self to him in these moments but only because he was her partner. She specifically stated that she allowed him to see parts of herself that nobody else was permitted to view. The position he held in her life allowed her to reveal a sensitive portion of herself when Anne usually engaged in hiding the stigma in other

contexts. Therefore, relational context was important to the strategy selection in how she managed her stigmatized identity.

Other survivors spoke about their confidence when managing stigma using an ignoring/displaying strategy. Shannon is a 34 year-old White female survivor who was burned in a household fire accident when she was 12 years old, receiving 12 % TBSA (scars on right shoulder, arm, and back). She is currently in a relationship and unemployed. Shannon mentioned experiencing bullies in her youth. When asked about their reaction to her, she replied,

Umm, just basically calling names, I mean, nobody could see it, except for the Jobst suit [pressure garment burn survivors wear for up to a year after initial injury] which I didn't wear that often anyways, but I never really had a problem with bullies cause they'd just say something stupid, and I'd just ignore them or whatever. Like, I'm not easily intimidated, and I wasn't then either.

Shannon's response to these bullies was to use an ignoring/displaying strategy or denial depending on their "stupid" response. Her confidence in herself indicated she did not accept others' perceptions of a burn stigma and was willing to challenge these notions as well as the applicability of this stigma to herself. However, in other situations when discussing her injury, Shannon and other survivors who fit this pattern found the reducing offensiveness strategy to be helpful.

*Reducing offensiveness.* Reducing offensiveness strategies, specifically transcendence, offer Dissembling Challengers a way to manage stigma by finding higher meaning from their burn scars. Shannon talked about the greater good that has come from her injury (as well as other tragedies in life) which typified the transcendence sub-strategy of the reducing offensiveness strategy. After giving some helpful advice for other survivors, Shannon began to reflect back on her own experiences.



I do consider myself to be very fortunate. Because every shitty thing that's happened, you know, I don't know if you're a spiritual person or not, but everything that's happened has actually in some ways benefited me, even if it's just to be able to help somebody else out.

By using the transcendence strategy here, Shannon acknowledged and accepted the applicability of this stigma to herself while still challenging others' perceptions. Much like the ignoring/displaying and denial strategies used earlier, this example also displayed Shannon's strength as it showed she is able to do something positive with what she perceives as negative. Additionally, this way of thinking and turning negatives into positives could indicate resilience for Shannon.

Overall, much like the survivors in the Challengers pattern, the survivors within the Dissembling Challengers pattern challenged others' stigmatizing perceptions of burn scars and used the reducing offensiveness strategy. However, what separated this group from Challengers was that Dissembling Challengers survivors also engaged in the Avoiding strategy in specific situations and as relational contexts dictated. While a significant amount of information has been presented so far about how survivors use strategies to manage stigma, the partner's experience is missing. The next section focuses on how a survivor's partner manages stigma messages related to their partner's burn status.

### **Partners' Strategy Use**

In this study, the romantic partners of burn survivors challenged others' opinions of stigma related to burn scars as well as the applicability of the stigma to the survivor. Romantic partners challenged or denied the stigma's existence by using the Denial and ignoring/displaying strategies. For example, Donald is a 36 year-old black male whose

female survivor-partner was burned down the left side of her body in a domestic violence incident 3 years ago. He said:

I think at first I had a problem with it, when people would look, you know, cause I was like “What y’all looking at? You never seen somebody, you know, with a scar on their arm?”... So, uhh, but that’s, that didn’t last very long. I think once, we go out of state once in a while, people stare, but it’s never something that makes me, umm, want to confront somebody. Never been that way.

In this quote, Donald reported initially using the denial strategy. At first, his approach was defensive, and he attacked others who would stare by challenging others who were staring at his survivor partner. This strategy is a form of logical denial known as attacking the accuser; it attempts to deny the existence of stigma (Meisenbach, 2010). Donald also admitted that this attacking strategy was temporary for him; he indicated he no longer chose this stigma management strategy when someone stared at his survivor partner. Therefore, by avoiding confrontation Donald engaged the ignoring strategy. Ignoring the stare, while his partner displayed her scar could be interpreted as Donald still denying the existence of others’ potential perceptions of stigma.

Tank also used the ignoring strategy. Tank is a 26 year-old Hispanic male whose female partner was burned in a fire as a child (13% TBSA). He has been with his survivor-partner for two years. When asked about his response to others staring at his survivor partner, he said:

I usually get pretty angry. Uh. I don't like to tell her that, just 'cause I feel like uh it wouldn't make her feel any better. But yeah, I definitely don't like it. I don't like to uh let her know that it ups-, it makes me upset, just 'cause I don't want her to feel bad about it. But no, I don't express it. Most of the time I just, I feel like they're [those staring] being nosy. Um. Maybe they're wondering what happened. Maybe they're, they've never seen many burn victims. I don't really know.

Interviewer: Have you ever talked to your partner about others staring?

Tank: It's it's kinda come up. Um. I don't, I just usually tell her, people are just stupid and they're nosy. Um. Unfortunately, I just really don't have a good explanation for it.

Despite Tank's anger, he indicated that he did not express his anger at others as he did not want to upset his survivor-partner. Tank acknowledged that there could be multiple reasons that others might stare at his survivor-partner, but seemed uncertain and dismissive of these reasons. He seemed agitated when discussing the reasons for staring and was even more bothered when he stated how he tries to explain it away to his partner. Though, he appears to sometimes express an attacking the attackers message to his partner ("people are just stupid"), he does not report actually sharing the attack with the people who are staring. Tank chose not to challenge their behavior in an effort to protect his survivor-partner's feelings. Not expressing the anger to the person sending the stigma message revealed his use of an ignoring strategy.

Like Tank, Claudia used the ignoring strategy. Claudia also admitted feelings of anger when others stared at her survivor-partner: "I feel bad. Um. I feel angry at people. Um. Helpless basically. Um. Just frustrated." While Claudia was angered, she was unable to respond with a challenge, therefore, her strategy of ignoring/displaying was a silent challenge. When asked why she thought others stare, she replied:

Because we're such a society accustomed to everything being like cookie cutter and everything like having certain ideas of beauty and stuff like that. That when something's different, be it, you know, whatever it may be, we just stare because we don't know any better, or we are accustomed and or raised to question or kind of curious about stuff like that. I think um especially now where it's like all in your face with social media and and all that. I think it's very-- It's very sad. It's very sad that society--it seems like everything's about the beauty outside and not so much attention paid to what's inside. I always, I always kinda knew that. It's just more um, much more in my face now. So yeah, I encounter that like much more frequent now.

Claudia recognized that society had distinct views of beauty that clashed with her own. She seemed to have very definite views but did not clarify why she chose to remain silent. While Claudia's silence can be viewed as ignoring the stigma, it seems that this strategy is not her preferred one ("I feel...helpless basically"), suggesting that sometimes what appears as a strategy of ignoring is not all that strategic.

Denials are a useful strategy for managing stigma for some partners. Avery, whose survivor-partner is Charles (who has a TBSA of 50 percent), discussed using the denial strategy. When asked how he responded to others staring at his partner, he replied:

I may comment, on the funny side, but still that has a, a wisp of, uhh, kind of defensive, or give something that people can learn from, or simply, depending on the, umm, person or the place, umm, I may just leave it at the look.

Avery's response gives a few options depending on the given situation or interpersonal context. However, each of these options involved denial strategies. Either Avery uses humor to dismiss/challenge the other's actions (though he acknowledges how that may be defensive, what SMC might call accepting of the stigma) or he may attempt more proactively to reeducate them. Either way, Avery challenges others' perceptions of survivors as stigmatized individuals.

Other partners found logical denials to be an effective way to manage stigmatizing situations. Bette is a 69 year-old White female whose survivor-partner, Richard, received 18% TBSA (scars on face, groin, legs) 22 years ago in an automobile explosion. She shared her experiences:

I think that the co-survivor, one of the things we do is we become very sensitive and protective of our loved one. And that doesn't matter whether it's a spouse or a child, you know. So we become aware of people looking. So as those years progressed, and three years and five years and ten years, um. We'd be out in a mall and you'd see somebody whip around. Um. And in the early years, they, of course, they looked much more, especially when Richard was having his reconstructive. The first five-- The first three years were always difficult. People

were always staring. And I can understand why they'd stare. I handled it better, but that doesn't mean I didn't see it. I just handled it better... One night, we were in a restaurant, and the table next to us, this man was just glued on Richard. And um for whatever reason, I was just not in an OK place, and I turned on this man and I said, "Excuse me, if you have a question, ask. We'll be glad to tell you." And the guy sort of like, you know, backed up. and he could see I had a bad -- And I was not polite when I said it. And I said, "My husband was a burn injury. You want to know about it?" "No, no, no." And he turned around, and that was the end of that. Uh. And that was the only time that that I ever had a real problem with it. And, you know, and I don't know what made me react that way.

In this instance Bette talked about feeling like she handled some situations better than others. Specifically in the last situation, her words offered to educate a person, but mostly she used a logical denial to attack a person who was staring for too long at her partner. Bette said that being a co-survivor makes an individual protective of their survivor partner. Perhaps this notion of protectiveness drives partners' selection of strategies that seek to challenge the stigma.

Finally, some partners may have survivor-partners with low TBSA or scarring in hidden locations that impacts the potential for using certain stigma management strategies. For example, Jim, whose survivor-partner has a TBSA of 15%, did not even notice others staring at his partner's scars: "I mean maybe if we're at the beach. I mean 'cause it's [the burn scar is] on her back, if they're going to stare, they're going to be behind us." Therefore, sometimes the partner ignores stigma communication because they do not perceive it occurring.

Overall, partner stigma management was distinct from that of survivors. Partners used denial and ignoring/displaying strategies only. While each of the survivor patterns incorporated the reducing offensiveness strategy, their partners never mentioned it. Partners' focus was on challenging others' stigmatizing perceptions.

## Summary of RQ1

Burn survivors and their relational partners each managed stigma in different ways. Partners managed stigma by simply challenging others' perceptions. They used the denial and ignoring/displaying strategies exclusively, while survivors shifted among a wider range of stigma management strategies. The current findings showed how survivors shifted among stigma strategies using the following four patterns: Accepters, Situational Adopters, Challengers, and Dissembling Challengers. Accepters used the accepting, avoiding, and reducing offensiveness strategies. Situational Adopters shifted among the accepting, avoiding, reducing offensiveness, denial, and ignoring/displaying strategies continually. Survivors in the Challengers pattern shifted among the denial, ignoring/displaying, and reducing offensiveness strategies. Finally those within the Dissembling Challengers pattern found the avoiding, denial, ignoring/displaying, and reducing offensiveness strategies to be useful in managing stigmatizing situations.

Challengers and the Dissembling Challengers were similar in their strategy use as both groups relied on challenging others' opinions of burn stigma. However, the survivors within the Dissembling Challengers group sometimes also used the avoiding strategy to engage in hiding behaviors, indicating that in some situations or relational interactions, they may be accepting other's stigmatization of their burns. While the Situational Adopters used five of the six stigma management strategies as needed, the Accepters used all of the strategies except those in the denial category (i.e., denial and ignoring/displaying).

Across each of the four patterns, the reducing offensiveness strategy was used by all of the survivors interviewed. Many survivors, such as Jennifer, admitted that it was "a

long process” to begin to think about their injury “in a different way.” They went from feeling ashamed and hating the way they looked to finding uniqueness and sometimes even seeing the injury/scarring as a miracle. The consideration of stigma can lead to consideration of how survivors and their partners construct the survivor’s sense of sexuality. Results indicated less co-construction of stigma management by survivors and partners than expected; however a clear co-construction of sexuality emerged. The next section of the chapter discusses the co-construction of survivors’ sexuality by survivors and their relational partners.

### **RQ2: Sexuality**

Research question two asked how sexuality was enacted/co-constructed by burn survivors and their relational partners. Survivors and their partners co-constructed sexuality in four specific ways: as feeling not sexy, having a fragile sexuality, being a new normal, and not being impacted. First, many survivors enacted their sexuality as feeling not sexy. Many survivors struggled with their body image after the burn injury and found embracing and enacting their sexuality to be a challenge. Next, an enactment of fragile sexuality emerged from the talk of some survivors and partners. Very often partners of survivors would construct survivors as having a fragile sexuality in an effort to be cautious of the survivor’s injury. Sexuality as being a new normal is often experienced by many survivors and their partners. This co-construction of sexuality is about getting used to the survivor’s new body and the sense of sexuality that entails. The final way in which survivors and partners discussed the co-constructed sexuality of survivors was that the burn scars had no impact on the survivor’s sexuality.

Each of these constructions of sexuality highlighted components of the survivor's sexuality such as body image, satisfaction, intimacy, and behavior. Sexual behavior and body image, components of sexual identity, were the two most salient features of sexuality as constructed by burn survivors and their partners. Each of these components is discussed within the context of each co-construction of sexuality. In contrast to the stigma results where partners made distinct constructions from survivors, here, sexuality was more of a co-construction between partners and survivors. Since there are four ways in which sexuality was co-constructed by survivors and their partners, each co-construction is discussed separately.

### **Sexuality as Feeling Not Sexy**

The first way that survivors and their partners enacted the survivor's sexuality was as someone who is not sexy. This enactment included survivors feeling shame and self-consciousness for their body. As they discussed the survivor as not feeling sexy, participants mentioned influences of beauty standards, body image, and strategies for managing this co-construction of sexuality.

**Influence of beauty.** Survivors discussed feelings of shame and self-consciousness that come from survivors' own concepts of societal beauty standards. Western notions of what is beautiful guided survivors' everyday interactions with their partners. For example, Anne, who had 48% TBSA and had talked about reluctantly letting her husband see her burn side, also talked about a time in which she was engaging in sexual activity with her partner:

You know, when you're on your back and you're supposed to be like looking like a goddess, and it's all wonderful and hot and heavy. Well, if I turn my head so then my hair falls back [exposing my burned scalp], and it's just very vulnerable-feeling. So I, several times, I've lost the whole feeling in the moment because I



realize I just-- I basically have a good side and a bad side... You're supposed to have this pretty sexy hair, THAT hair, you know... I'm thinking that's not what they're looking at. They're looking at IT, you know.

Thus, conceptions of what a body is supposed to look like and what a survivor's body actually look like may run through a survivor's mind during sexual activity. For Anne, she felt like she was supposed to look like a goddess during this sexual act but also felt vulnerable about her scars because in her experience, goddesses don't have scars. Anne reiterates Western societal beauty standards when she says, "You're supposed to have this pretty sexy hair, THAT hair." Anne felt because part of her hair was missing, her partner would be focused on that scarred aspect as opposed to the pretty, sexy hair. The concept of sexy hair constituted sexiness for Anne but thinking her partner was focusing on her unsexy hair and scar pulled her out of the sexy moment.

Interviewer: So when you're laying there on your back and he's looking at you; what do you think he's thinking in his mind when he sees you?

Anne: Like "That's not sexy." [both laugh]

Interviewer: Have you ever asked him what he thinks when he's looking at you?

Anne: Uh, not in that moment but in other moments. Where we sit in the living room, you know, his chair and then my chair. And, you know, if he looks across at me, he's looking at my bad side. And I haven't even called it my bad side in so long. But um because I had kind of tried to drop that negative look at it. But um I said to him, you know, I was like, "You know? I just realized that when you look over at me, that you um are seeing all the parts that I usually don't let people see." And he was like, "Anne, I don't even see that anymore." So I think that whenever we are being intimate that he's actually not really seeing it the way that I think he's seeing it.

Anne acknowledged that she often felt like her partner was staring at her scars and thinking "That's not sexy." However, conversations they have had where her partner has told her that he does not even notice the scars anymore are part of challenging her self-construction as not sexy, that is, while Anne has constructed herself as not sexy, her

partner works to reconstruct this not sexy image by telling her he does not see the scars anymore.

Renee, who was burned as a child and met her husband many years later, mirrored Anne's experiences of feeling not sexy. Renee still questions why her partner would find her attractive, despite the fact that he dated, married, and had children with her. Renee says, "When I don't feel attractive, it's hard for me to be, to be willing to be intimate... he still finds me attractive, and I'm not entirely sure why sometimes. And so that makes it [intimacy] a little more difficult." Despite the fact that her partner tells her he finds her attractive, she still doubts him because of the scars she bears on her body. This inability to feel attractive or sexy challenged her ability to be intimate with her partner. Yet, because survivors do not look like traditional standards of beauty, it is often hard for them to feel sexy.

**Body image.** Body image was a major component of how survivors constructed sexuality as not sexy. Perceptions of their bodies were often not positive, especially in the early years after the injury. Survivors talked about how often they would experience moments of shame and a fear of rejection. For example, when asked about how others might perceive her scars, Shannon indicated that "at first I was really...I, I guess ashamed." Sometimes the sense of shame is so deep that it causes a person to feel not normal. Claudia, a 36 year-old Hispanic female said that her survivor partner and she had not had sex since his injury 7 months ago from a car accident where he sustained 85% TBSA. When asked if her survivor partner said anything about the way he looks, Claudia reported "there's always something to say, you know, about how he looks and how, you know, I could be, you know, he said a few times that "you could be with

someone 'normal.'” Choosing not to see themselves as normal indicated poor body image on the part of the survivor. Failure to perceive himself as normal as well as a lack of sexual interaction may be interpreted as a construction of not feeling sexy on the part of the survivor.

A fear of rejection and sense of shame were common themes for survivors in their not sexy experiences of body image and sexuality. Jennifer, a survivor, said that:

In that very beginning, I wanted to share myself with him [partner], but I was very scared that um I would be rejected at some point... I mean definitely a huge barrier, um, in our relationship was, you know, my physical, my self-image of myself, as far as our sexual intimacy. That's just going to be something that I deal with for the rest of my life... and it makes me sad... because I do wonder, you know, what I would be like if um I didn't have uh those, you know, the scars.

How Jennifer perceived herself as sexy or not sexy impacted her relationship. While Jennifer held a negative self-image of herself and feared rejection from her partner.

Furthermore, Jennifer struggled with the not sexy construction of sexuality when she talked about having to deal with her negative self-image for the rest of her life.

Therefore, each of these survivors indicated that body image impacted their constructions of sexuality as not sexy.

**Managing not sexy co-constructions.** Some survivors and partners found strategies to manage the sexuality construction as “not sexy” in order to move past the body image concerns. While Charles, a survivor, experienced self-consciousness during sex early on, he said he had “gotten used to it.” After getting used to his scars, he was able to tell his sexual partners, “What you see is what you get. If that bothers you, then you really don’t know me, you don’t want to know me, if you let it stop you, the scars, stop you.” Initially, Charles managed his sexuality by accepting others’ constructions of

himself as not sexy. While he seemed successful at accepting his not sexy construction, other survivors managed their feelings of not sexy in different ways.

Additionally, Jennifer managed not feeling sexy by becoming other-focused. Becoming other-focused during sexual experiences allowed the survivor to shift the focus off constructions of their own body and self as not sexy to focus on their partner and physical feelings. Jennifer enacted being other-focused to manage her sense of self as not sexy, as she said you can

just [allow] yourself to enter into the moment and not think about yourself, but to think about the other person. If I think about me, then oh, my goodness, like that's such a barrier because I don't feel- I, you know, I never feel sexy.

Focusing on her partner rather than herself during the sexual experience allowed Jennifer a way to take her mind off her scars: "I don't focus on how I look, but I focus more on how I feel." By altering her focus, Jennifer was able to engage with her partner sexually without the feelings of self-consciousness that previously restricted her sexuality.

Similar to focusing on someone else or the physical feelings, feeling like they are someone else was another strategy used to manage the not sexy co-construction of sexuality. In response to focusing on one's partner, Jennifer reported feeling like she is another person or not like herself during sexual experiences. When talking about body image concerns, Jennifer said, "if I can focus on him, and then in those moments, he really makes me feel like I'm somebody else. You know? He really takes my mind off of that." Feeling like another person, allowed the survivor the opportunity to forget their current body image woes and engage sexually with their partner. Focusing on one's partner or feeling like another person may boost the survivor's sexuality in such a way to provide a healthy intimate relationship, thus reconstructing the not sexy dynamic.

In terms of co-construction, most of the partners were trying to get their survivor partners to stop constructing themselves this way, but survivors did sometimes mention romantic partners from their past who had reinforced constructing the survivor as not sexy. For example, Charles mentioned that during sex, “one guy who I was with, he wanted me to wear a shirt.” In this example Charles was asked to cover up his scars so his partner would not have to look at them during sex. So partners would sometimes construct the survivor’s sexuality as not sexy when they responded to survivors in a negative or unsupportive manner toward the scarring.

Overall, survivors’ (and occasionally partners’) body image perceptions were found to make some survivors feel not sexy when enacting their sexuality. While the survivor struggled with feelings of un-sexiness, most partners attempted to reconstruct the survivor’s body as sexy. Additionally, Jennifer also attempted to reconstruct their own feelings of un-sexiness by focusing on their partner and/or by viewing themselves as not themselves when engaging in sexual activity. While this section focused on how the survivor enacts sexuality as not sexy, the next section concentrates on how sexuality within the survivor-partner relationship may sometimes be constructed as fragile sexuality.

### **Sexuality as Fragile**

The second way in which sexuality was constructed by survivors and their partners was as a fragile individual. Survivors and their partners primarily constructed sexuality as fragile for similar reasons, to protect the injury. Fragile sexuality was constructed by some partners of burn survivors in an effort to protect the survivors from pain but also from further worry. For example, as noted earlier, Claudia and her survivor

partner have not had sex since his injury seven months ago. While she felt that sex needed to come back into the relationship, she resigned herself to celibacy as she didn't know how to engage her partner in conversation about such a delicate topic: "I don't want to make it uncomfortable in case he's not ready, and then that's just going to give him something else to kind of to worry about." Claudia set aside her own sexual satisfaction until her partner was ready to participate again. She constructed her survivor-partner's sexuality as fragile in an effort to protect him from further worry.

As both survivors and partners worked to construct sexuality as fragile, initial sexual activity after the injury happened anywhere from immediately upon release from the hospital for some, to six months to a year later for others. Richard, a survivor, indicated that it did not take long before sexual activity was on his mind again.

It was within the first couple days of being home...And just because I was burned, that didn't stop my uh I guess hormonal flow...She probably wasn't as open to it as I was, 'cause she was concerned about hurting me or-- You know, I had one really badly injured knee that it was there, and then I had grafts in my groin area. So they were all fresh and wrapped. And um so there was a fear there that she was-- It wasn't that she wasn't responsive. She just was concerned. And that was kind of an awkward time.

From this quote, Richard seemed to feel that his partner had constructed him as fragile as he reported her above to be "concerned." Many partners reported a fear of injuring their survivor during sex and let the survivor take the lead on deciding when and how sex should occur. While Jim, a partner, noted that he waited "a long time," he did not mention expressing any remorse about the situation to his survivor-partner or during the interview.

Sometimes, survivors themselves constructed their sexuality as fragile, perhaps in order to protect their injuries. Benjamin, a 63 year-old White male who was burned in a chemical explosion in the workplace, received 30% TBSA. While Benjamin waited for

his injuries to heal for a couple of months before engaging in sexual activity, he found “the process [sex]...had to change.” Survivors often leave the hospital wrapped in bandages and are unable to perform sexually in traditional positions. Therefore, they must be willing to engage in some amount of experimenting or wait until those sites become comfortable. For example, Jim said he and his survivor-partner, Dawn, waited from six months to a year because she was not “able to feel comfortable, [find a] comfortable position.” In her interview, Dawn said, “it's uncomfortable to lay on my back, so we really didn't have a lot of physical intimacy, no intercourse or sex or anything like that.” In this instance, both Jim and Dawn co-constructed her sexuality as fragile in that she was not able to be comfortable to perform sexually. Benjamin said “you know, you typically think of, you know, the positions on the, on the bed, that I couldn't do that. So, it was just, different. We had to, we had to find, uh, different ways to make love.” Experimenting with other positions than the traditional missionary position allowed this couple to continue their physical sexual relationship. In this instance, Benjamin constructed his sexuality as fragile as he specifically talked about what positions he couldn't perform.

Some partners were not in a relationship with their survivor during the time of the injury. Their constructions of sexuality as fragile were often based on how the scarring looked. Michelle, a 30 year-old White female, is the partner to Wu who was burned 12 years ago when his hair was accidentally lit on fire (54% TBSA). She has been dating Wu for one year. When discussing their sexual relationship, Michelle said:

Really the only, the only um, not precaution, but the only thing I was still cautious about was like his skin, his skin graft. It just looked so paper thin, “I'm not trying to skin him!” [chuckle] by like holding him or grabbing him or something.

In this quote, Michelle is constructing Wu, the survivor, as fragile in their sexual

experiences. She said she feels she has to be cautious because of how his skin looks. She never referred to anything said by Wu or anything she has read, she simply constructed his fragility based on the perception of his “paper thin” skin. Therefore, during their sexual experiences Michelle felt the need to be cautious about grabbing him, thereby constructing Wu as fragile.

Survivors who were not currently part of a long term relationship tended to construct their own sexuality as fragile but flexible. Many survivors reported that they must engage in a conversation with a potential partner to prepare them for what they will see or how sex might be done, thus constructing fragility. These survivors resisted the framing of themselves as a “do not touch” type of fragile. Rather they were working towards constructing a “handle with care” construction of fragility. For example, Jason’s body was limited in its ability to stretch and, therefore, he must “explain to them, all over again, what's going on and...what [he’s] capable of.” Here, Jason has constructed himself as sexually fragile. While Jason knows that sex is not as easy as it once might have been, he feels that most partners are willing to participate after an honest conversation about expectations. These survivors are clearly engaging in sexual behavior during the dating process and have found upfront honesty about their specific situation to be a useful approach in constructing sexuality as fragile on their terms.

In summary, fragile sexuality is about constructing the sexual experience in a way to protect the survivor. Who has constructed the sexual experience as fragile, survivor or partner, will offer clues to what the individual may be attempting to protect the other person from. Partners often constructed their survivor-partner’s sexuality as fragile in an effort to protect them from worry (as with Claudia) or further injury to the burn site (as



seen with Michelle). Survivors constructed their own sexuality as fragile, but flexible in an attempt to prepare their partners to engage them sexually. This section has shown how some survivors and partners constructed the survivor's sexuality as fragile, and the next section focuses on how survivors and their partners reconstruct their sexuality as a new normal.

### **Sexuality as Being a New Normal**

Reconstructing sexuality as a new normal is the third way that survivors and their partners enacted survivors' sexuality. Richard said that the burn survivor community often discusses "coming to terms with [their] new normal." Many survivors' bodies undergo dramatic transformations, and the process of coming to terms with those changes in relation to their sexuality reflected the notion of a new normal for some participants. This new normal indicated that the survivor should accept their new body as sexual no matter how it appeared to self or others. The idea of the new normal is simply incorporating the burn scars into one's sexuality. This section discusses the characteristics of the new normal and details strategies for managing it.

**Characteristics of the new normal.** When engaging in sexual activities, the survivor has to consider their newly scarred bodies. Richard often counseled other new survivors by telling them:

Skin is the wrapping paper of your life. If you get a beautiful present for your birthday, Christmas, whatever, --got bow, wrapping paper on it. What do you do? You rip it all apart, throw it on the floor, and you get to what's inside. That's all skin is.

Therefore, the new normal was about redefining the way survivors viewed their bodies post-burn. Richard's statement comparing skin to wrapping paper was meant to encourage survivors to shed their preconceived notions of beauty and adopt a new normal

based on their own body. By redefining sexuality to fit the survivor and their partner rather than societal standards of beauty, survivors may encounter fewer issues with body image.

As body image was a significant struggle for survivors and their partners, finding a new normal to balance the changes became important. The changes that a survivor went through required patience from the partner, and it was likely that the survivor would be forever changed by the injury. Donald explained how his survivor partner has changed since the injury.

She isn't quite forthcoming, sexually as she used to be. She definitely slides away a little, doesn't like to show her boobies... she doesn't like to wear low-cut shirts... she was one of those women who really owned their sexuality when we first met, so she's much different than that now, like I said she's very, she's very, well if I can say something, she's like me, I'm a laid-back dude, like, if there's a party going on I'll probably be sitting in a chair somewhere, drinking a beer and just watching everything going on. She was probably the one that I was watching at the party, you know, the lively one, she started the party. She's not like that anymore, she'd probably be sitting next to me now... She definitely, she doesn't own her sexuality like she used to.

As Donald admitted to being a laid-back individual, he felt that his partner “was more than I could handle, so right now she's at my level.” Encouraging her to get back to where she was before the burn, sexually, may not be what was desired in this relationship. Donald continued, “I think we're right where we need to be at, I don't know how she's going to be in a couple of months.” While Donald admitted that he is quite comfortable with his partner's new normal of sexuality, he also acknowledged the potential for change on the horizon.

**Managing the new normal.** One way in which participants managed the new normal, was to re-engage in sexual activity. Survivors talked about just “doing it.” In fact, Anne offered the following advice to new survivors about intimate relations:

Don't not do it [have sex], um and don't, you know, not get intimate just because you're afraid of injuring it [burn site]. And then don't not get intimate because you're afraid that your partner isn't going to want to. Um. But yeah. The main thing, I would just say if the doctor said it's [sex] fine then by all means, you know, do what you both think is going to feel good.

So Anne was telling other survivors to not be afraid of further injury to themselves or of their partners. She said to just do what feels good for the survivor in terms of sexual behaviors. This advice typified the new normal as it encouraged survivors to re-engage in sexual activity much like their previous activities before the burn.

Another strategy for managing the new normal involved the survivor feeling comfortable with their burns scars. Some survivors mentioned that when they felt self-conscious about their scars, intimacy was challenging. Renee's advice to other survivors about body image and sexuality, was that:

until you're comfortable with yourself, it's [intimacy] going to be a struggle. And I mean whether or not you can become comfortable with your scars is going to play a huge role in how comfortable you are with intimacy. Um. You know, if you're with the right person, they're not going to see it as an obstacle. But you also have to be willing to accept that it's not an obstacle.

Renee's advice indicated the survivor should find some amount of comfort in their own skin. Therefore in accordance with Renee's experience, once comfort and acceptance has occurred, greater fulfillment may be achieved sexually.

A third strategy for managing the new normal construction of sexuality was for partners to re-define their physical attraction for their survivor-partner. Burn scars may alter a survivor's body dramatically. Therefore, how a partner responds to the scarring can impact their physical attraction to the survivor. By redefining their physical attraction for the survivor, partners are managing the new normal. For example, Avery, Charles's current partner, talked about how he perceived the attractiveness of his survivor-partner:

He's attractive in so many other ways. It doesn't necessarily have to be attractive physically to me, and what is attractive? What is, you know, we are always, nowadays, today here and now where I'm at, attraction to me doesn't umm, doesn't manifest, or it doesn't translate into a physical thing. But, even, since we're speaking about the physical, even this now is attractive to me because to me, now it's a map, his life story, it's a testament that he was wearing so amazing, so gracefully, so touching, that this is his life story to me, this is like, the most impressive, the prettiest, unique umm, things, garment that he can have that is only his. You know, and I'm there on the outside to marvel at, I mean, I honestly, like, I'm so used to it now because, you know, we've been together for some time and having, uhh, sexual relationship and all that, so obviously. It's, he's my other half.

While Avery met Charles after his burn injury, he admitted that his survivor-partner "was the antithesis of the person I would be attracted to physically," however ,getting to know his partner and establishing a connection enabled Avery to see past the scars.

In sum, body image has been a dominant factor in how survivors and their partners construct sexuality in this area of the new normal. When survivors and partners embraced the new normal, they accepted the survivor's body image as is and reconstructed sexuality based upon this new look. The new normal is about embracing one's current body and getting back into sexuality and doing what Anne says "*feels good.*" Some participants mentioned that sexuality within the relationship had changed (such as happened with Donald and his survivor-partner), however the change was comfortable. While many survivors have embraced a new normal, experienced a fragile sexuality, or felt not sexy, others survivors and partners constructed their sexuality as not impacted by the burn scars.

### **Sexuality as Not Being Impacted**

The final way in which survivors and partners constructed their sexuality was as not impacted by the survivor's burn scars. This section speaks to a number of ways in which the co-construction of sexuality was represented within the data.

When survivors and partners were asked if their sexuality was impacted by the burn injury, many were quick to deny an impact. Isaac is an 18 year-old single White male who was burned as a child when he stepped on hot coals, receiving 2% TBSA (scars on foot). When Isaac was asked if his burn scars ever impacted his sexuality when dating, he said:

No. But, I mean, I've got scars everywhere. Every time I see one of my friends they're like, "What did you do?" That one [pointing to elbow]...I did this, that one [pointing to shin] I did that, that one [pointing to thumb] I cut my thumb off, that one [pointing to wrist], I don't even know how I did that one last night, to be honest with you, I couldn't tell you. I've just got scars everywhere, so...

Isaac perceived his burn scar as one of many other types of scars that populated his body.

Indeed his burns may not even constitute the biggest scarring on his body at 2 percent.

When asked about intimate moments with a partner, Isaac said,

I mean, it's not like, you know, open heart surgery, like big, 18-inch long scar, but my scar on my foot, you know, three and a half almost four inches long, I think, and you know, if a girl sees that I kind of have to explain the story, you know, skin grafts, and sometimes I don't even go into the whole burn thing, just because it's kind of awkward situation to be telling at twenty minute long story, yeah. So it's just skin graft, they put the skin under my toes, no big deal.

The way in which Isaac chose to dismiss his burn scar/skin graft indicated it was a non-issue for him and should be perceived as such by others in the same way. Therefore, he did not perceive his burn scar as impacting his sexuality in any way. While Isaac was single, Dawn, (15% TBSA, scars on back and legs) was a married survivor when she sustained her burn injury. When she was asked how her intimacy and sexual relationship has changed she replied, "I don't think anything changed, then. I don't feel like it [my burns] hindered or made it [sexual relationship/intimacy] better. I mean I don't think it's [sexual relationship/intimacy] really changed at all." Dawn's partner, Jim echoed her statements when asked if anything had changed in their sexual relationship since the

injury. “I would say no. You know, we're pretty, we're pretty basic with our intimacy, so the conditions are the same.” Therefore, despite the difference in being married as opposed to being single, both Isaac and Dawn felt that their burn scars did not change how they had constructed their sexuality. Furthermore, both Dawn and Jim co-constructed their sexuality in a similar manner.

Sexual satisfaction within the relationships of burn survivors and their relational partners was important among those who constructed sexuality as not being impacted by the injury. Many survivors and their partners issued very general and direct statements about their satisfaction. Tank, whose survivor-partner, Riley had a TBSA of 13%, said, “I'm pretty satisfied, uh, with what we have.” When asked about his first intimate experience with his survivor partner and what it was like to view her body, Tank replied,

I see it as uh anybody else would be uh seeing, ... their girlfriend's body. I I'm attracted to it. I like it. Uh. You know, she's, you know, just like anybody else would see it really. You have to be attracted to somebody. You know, ... you can't be with somebody you're not attracted to and-- I'd I'd say uh viewing her body [chuckle] has never been a problem.

Clearly, Tank is attracted to his survivor-partner but the key is that he does not perceive her body any differently than others he might be attracted to. Tank's survivor-partner's burn scars do not seem to inhibit his attraction for her in any way. Lucy (4% TBSA scars on her left leg), a single Black survivor who was six months out from her burn injury also didn't think her sexuality would be impacted by her scars. When asked if sexual partners might have any concerns about her injury, Lucy said “they probably wouldn't even be thinking about uh just my injury at that time. [laugh].” Lucy felt that her sexual partners would be focused on the sexual activity at hand rather than any scars she might have, thus leaving no impact on her sexual experience.

Others constructing sexuality as not being impacted talked explicitly about feelings of sexiness rather than challenges. When asked if he experienced challenges with feeling sexy, Wu said “I’m plenty sexy.” He went on to say, “I don’t care. I’ll sit down and strut around like, you know, you know, da da da, da da da [strip tease song].” In fact, Wu’s partner Michelle said that:

Wu really embraces everything about those scars. And that, to me, is attractive. And just kind of the, just kind of the way he owns those scars and the fact that he’s OK with me touching them and ogling them and looking at them and kissing them and enjoying them. Like I’m not, it’s not the scars per se, it’s the uniqueness of the skin.

The way in which Michelle talked about how Wu embraced and owned his scars indicated that she thought he had confidence regarding his scars. This confidence in how he embraced his scars attracts Michelle. While Michelle attributes Wu’s confidence to how he owns his scars, Wu claimed to have been charismatic before his burn injury:

Yeah. I mean I’ve always been charismatic. I come from a very charismatic family. You know, they’re all, they’re all musicians and actors and stuff like that. So--comedians. And so I always had that. And I I took this whole burn thing really well. And I think that girls pick up on that.

Wu’s confidence was attractive to Michelle and allowed this couple to engage in sexual experiences that were not necessarily impacted directly by burn scars. While Michelle indicated that she is attracted to how he embraces the scars, his charisma was present before the scarring occurred. Therefore, if there were no scars, it is likely Michelle would find another aspect of Wu’s personality that he embraced to be the focus of the attraction.

The sexual orientation of survivors and partners had a small role in the construction of sexuality as not being impacted by the injury. While the majority of the participants interviewed for this study identified as heterosexual, four identified as gay or

lesbian. Sexual orientation did not seem to play a major role or difference in delineating between survivors in terms of sexuality. However, Shannon, noted that

one of the things about being gay is that...we kind of already had to do the self-acceptance thing, and already been through the ringer of pretty much being told that we're terrible people and you choose to be this way.

Therefore, for Shannon, sexual orientation played a role for defining herself personally and sexually. Even in Shannon's early years, she reflected on her mom telling her that she would not "be getting asked out to any dances or anything [due to burn], but I was kind of nontraditional even back then so it was not really something that stuck with me." Even though Shannon labeled herself as nontraditional in those years, she was not formally out and had not considered dating. Therefore, having scars did not seem to affect getting asked out on a date. Shannon claimed that "I've never really felt like, I've never really had rejection and not been able to meet someone if I wanted to." So it seemed that Shannon's burn scars have not impacted her sexuality despite her mother's early comments.

Partners also co-constructed sexuality as not being impacted as they detailed first sexual experiences post-burn. Under a previous construction of sexuality, fragile sexuality, Richard detailed his first sexual experience post-burn with his partner Bette. He felt she was concerned about him and indeed Bette had constructed his sexuality as fragile. However, Bette had a slightly different approach to the story. In fact, her story began with a sexual experience that occurred while Richard was still in the hospital.

Because of his hands being fully bandaged, I could touch his arm, but you couldn't sit and hold somebody's hand. Um. And there were still tubes and wires and crap everywhere. So I took to sitting at the end of the, end of his bed. And his feet, you know, you could see his toes 'cause they had no bandages on them. Um. Because where the grafts were, you know, on his foot or on his legs. And I would sit at the end of the bed, and I would put my finger wrapped around his big toe, and I would sit there and read a book to myself, or I'd read the newspaper to him



every day. And that's where I would sit. Well, this one day, I don't know how I was sitting or what was going on, but all of a sudden, he reached his foot out and started very consciously, 'cause I mean he wasn't--he was no longer-- He was sort of in a, in that in-between state. I mean he was alert but not there. But it was a very conscious thing, that he took his foot and he chose to rub my breasts in a very definite manner. You know, it was just like, you know, a guy's going to, you know, be caressing your breast. [laughing] But that's what he was doing with his foot. I just thought, "Richard!" So for him, sexuality was still functioning well and he was there, I guess. You know, uh. The day he had a day pass, he was [chuckling] very interested. And we went home and we did!

I: OK. So that was your first sexual experience, on the day pass.

R: Yeah, yeah. So being sexually intimate for him never left his psyche. Um. I was worried because uh with the injury to his knee, he certainly couldn't be in uh- - I just forgot the word I wanted to use. The very standard position. It's got a name.

I: Missionary?

R: Missionary. I couldn't think of the word. It just left my mouth. It was gone. Um. You know, we certainly couldn't do the standard missionary position. Um. But, you know, we were, we were not so old that that was the only thing we did. So.

I: So that was something you had to work around when you guys got home. You had to figure out--

R: We didn't--no, it wasn't even a matter for us, it wasn't a big deal. "OK, we can't do this, but we can sure do it this way." But we didn't--you know, a lot of couples, especially depending on, not so much more now with younger couples. But with older people, that may be the only position they ever had sex in. So um sometimes if you're in a position that you need to counsel family, you need to be comfortable to talk about sex. And ascertain, you know, if that's the only way you have sex, there's some other things you could do. Um. But for us, we were fairly inventive to begin with, so that was never an issue. It was just like, "OK. If we do it this way, it's no big deal. We can even do it another five ways that would be no big deal." You just can't do it that way.

In this excerpt, Bette detailed her perceptions of the first sexual experiences after the burn trauma with Richard. She noted how Richard's sexuality was still present ("sexuality was still functioning well") despite the tubes and wires in the hospital when he began to massage her breast with his foot. And while Bette acknowledged being worried in some

regard (“I was worried because uh with the injury to his knee, he certainly couldn't be in... The very standard position”), the worry seemed to be mostly targeted to finding the right position so they could engage in sexual intercourse without injury to her partner as opposed to constructing her partner as a fragile individual. Bette seemed to be focused on how they were getting their sex life back on track after Richard’s trauma. The discussion about finding positions that were favorable indicated that the injury was not impacting the relationship in a meaningful manner sexually, and she explicitly noted “for us, it wasn’t a big deal.”

Overall, this section detailed the final way in which survivors and their relational partners constructed sexuality as not being impacted by the burn scars. Survivors in this area felt their sexuality was not impacted by burn scars. Partners reported feeling physical and emotional attraction for their survivor-partners despite the scarring. Both survivors and their partners who talked about sexuality this way described sexual activity that indicated satisfaction with their experiences.

### **Summary of RQ2**

Feeling not sexy, experiencing fragile sexuality, reconstructing sexuality as a new normal, and understanding sexuality as not being impacted are four ways of constructing sexuality enacted by survivors and their partners. Survivors’ and partners’ accounts of sexuality were presented within these four ways of enacting sexuality. While some survivors and partners reported that their sexuality was not impacted, others attempted to embrace a new normal. This new normal was about accepting the survivor’s new and different sense of sexuality and body despite its scarring. Some survivors and partners constructed the survivor’s sexuality as fragile in an attempt to protect the survivor from

further worry or injury. Other survivors enacted sexuality through moments of feeling not sexy while partners attempted to reconstruct them as sexy. Each of these enactments of sexuality demonstrated how survivors and their partners co-constructed sexuality within their relationships.

### **Summary of Results**

This chapter has presented the findings regarding burn survivors' and partners' management of stigma and constructions of sexuality. The present study uncovered stigma management strategies used by survivors and relational partners that stem from the SMC model. Relational partners had one clear pattern, which focused on denial strategies. Four patterns of stigma management emerged from survivors: Accepters, Situational Adopters, Challengers, and Dissembling Challengers. Reducing offensiveness emerged as a common strategy among all four survivor patterns. Stigma management was clearly constructed separately by both survivors and partners. However, sexuality was much more co-constructed. Sexuality was co-constructed by both survivors and relational partners in four ways: as feeling not sexy, as feeling fragile, as being the new normal, and as not being impacted. Implications and applications of these findings are discussed next in chapter five.

## CHAPTER 5: DISCUSSION

The purpose of this study was to explore burn survivors and their relational partners' lived experiences of stigma and sexual communication. Specifically, the study focused on how survivors and their partners manage stigmatizing communication as well as their sexuality post-burn. This chapter provides a summary of the findings in relation to each research question and also discusses the project's theoretical implications, practical applications, strengths, limitations, and opportunities for future research. This chapter begins with a brief discussion of the study's findings.

### Summary of Findings

This section of the chapter summarizes the findings presented in chapter four as they answer the primary research questions. The focus of this current study was to describe the lived experiences of burn survivors and their relational partners regarding stigma and sexuality. In order to meet this objective, two research questions were explored: (RQ1) How are stigmas reflected in/managed by burn survivors and their romantic partners? (RQ2) How is sexuality enacted/co-constructed by burn survivors and their romantic partners? In this section, results for each research question are reviewed in turn.

#### **RQ1: Stigma**

The first research question asked how stigmas were reflected in/managed by burn survivors and their romantic partners. Both burn survivors and their romantic partners revealed specific patterns of stigma management strategy use that aligned with Meisenbach's (2010) typology of stigma management communication (SMC) strategies.

As a review, Meisenbach's (2010) SMC strategy typology indicated six categories of stigma strategies: accepting, avoiding, avoiding responsibility, reducing offensiveness, denying, and ignoring/displaying. These categories were organized into four quadrants based upon the acceptance/denial of stigma applicability to self and the acceptance/challenge of public perception of stigma. Of the six categories of strategies presented in the typology, the participants in this study used all but the evasion of responsibility strategy.

In terms of how survivors and relational partners managed stigma, the findings suggest distinct patterns in the ways they employed various stigma management strategies. Furthermore, survivors and partners used patterns distinct from each other, suggesting that stigma was not co-constructed or managed together. Instead, the management of stigma was unique to each group. Therefore, each group's stigma management strategies are discussed separately.

Relational partners of burn survivors indicated that they typically used denial and ignoring/displaying strategies to manage stigma. These strategies fall into a single quadrant of Meisenbach's (2010) SMC model, which indicated that partners challenge others' perceptions of stigma. Partners did not talk about using the reducing offensiveness strategy, which was present in each of the four patterns used by survivors, making partners' stigma management distinctive. Perhaps because partners did not carry the stigma of the burn scars themselves, they were less likely to internalize the stigma and use accepting or avoiding strategies. Rather partners may have chosen to deny the stigma as a way of protecting and building confidence in their survivor-partner. This notion of protectiveness for the survivor may drive the relational partner's strategy choice. When

Bette, Richard's relational partner, discussed her experiences with staring at Richard she said, "I think that the co-survivor, one of the things we do is we become very sensitive and protective of our loved one." Bette's comment indicates that perhaps her strategy choices of denial and ignoring/displaying were based upon efforts to protect Richard.

Four categories of stigma strategy use patterns emerged from the interviews with survivors: Accepters, Situational Adopters, Challengers, and Dissembling Challengers. The first pattern, Accepters, included survivors using three categories of strategies: accepting, avoiding, and reducing offensiveness. Each of these strategy categories encapsulates one of three quadrants of the SMC model. The SMC model has four quadrants, one is not represented in this pattern. The missing quadrant represents denial strategies, which the accepters did not discuss using. According to the SMC model, accepting and avoiding strategy categories result from an acceptance of others' perceptions of stigma, while the reducing offensiveness, denial, and ignoring/displaying strategy categories indicate a challenge of others' perceptions of the stigma (Meisenbach, 2010). Accepters did not use any denial strategies, thus indicating they did not seek to challenge others directly. While the reducing offensiveness strategy seemed to be used, the specific sub-strategy of transcendence that was articulated may have been more for the survivor's general benefit rather than for challenging others' stigma messages and perceptions. For example, Dawn talked about how her injury has given her specific valuable qualities such as compassion and empathy.

I think I look at it [my burn injury] as it made me who I am today. It made me a stronger person and I think it's given me a lot more compassion towards other people... I feel like I can relate. I can truly empathize with the situation that their going through.

The way in which many of these survivors such as Dawn, used the transcendence strategy indicated they may have been trying to build resiliency (e.g., Holaday & McPhearson, 1997; Williams et al., 2003) more than simply trying to manage a specific stigmatizing situation.

Survivors in the next pattern, Challengers, used three slightly different strategy categories to manage their stigma: reducing offensiveness, denial, and ignoring/displaying. While the use of the reducing offensiveness strategy sounded the same as when used by those survivors in the Accepters group, Challengers also sometimes described choosing to challenge others' perceptions by using denial and ignoring/displaying strategies.

Of particular interest is that two types of individuals fell into this Challengers pattern: survivors with a very small and/or hidden burn scar or survivors with a previous history of stigmatization for some other characteristic unrelated to their burn. The latter type included survivors who mentioned previous experiences with stigmatization and staring in their lives (such as Richard who had a brother with Cerebral Palsy). Later in this chapter, the potential for future research investigating how these experiences may have impacted their choice of strategy use will be discussed.

The Dissembling Challengers pattern looks similar to the Challengers pattern but it adds the avoiding strategy category. This group of survivors differs from the Challengers because in specific moments or with specific relational partners, Dissembling Challengers chose to manage stigmatizing situations by hiding their burn scars. Interestingly, those within the Dissembling Challengers patterns were all women survivors. The main difference between this pattern and the Challengers is the addition

of the avoiding strategy. Perhaps, the addition of the avoiding strategy, specifically hiding the burn scar, was more applicable to women due to body image and outside pressures from society regarding beauty standards (Corry et al., 2009).

Finally, survivors within the Situational Adopters pattern, shifted among five (accepting, avoiding, reducing offensiveness, denial, and ignoring/displaying) of the six SMC strategy categories to manage their stigma. Evading responsibility was the only category of strategies from the SMC model that was not found in this pattern. Survivors within this pattern tended to adopt a strategy according to the contextual situation or relational nature of the person they were interacting with. All but one of the survivors in this pattern was burned as a child, indicating a significant amount of experience with their scarring overall by the time of the interview. Perhaps the experience many of these survivors had impacted the multitude of strategies they used.

Using humor as an accepting strategy was seen in both the Accepters and Situational Adopters patterns. While the SMC model indicates that using humor is an accepting strategy, it is possible that survivors may be using humor as a way to deny stigma. For example, when Avery, the relational partner to Charles, was asked how he responded to others' staring, he said the following: "I may comment, on the funny side, but still that has a, a wisp of, uhh, kind of defensive." Avery used humor to dismiss others which is indicative of the challenging axis of the SMC model, rather than the acceptance strategy category which the strategy is traditionally placed under.

Overall the findings relevant to RQ1 indicated four trends: absence of the evading responsibility category, consistent use of the reducing offensiveness category



across all survivor patterns, similarities among survivors within patterns, and pattern difference between survivor and partners. Each of these trends will be discussed in turn.

First, the evading responsibility category was not present in any of the participants' experiences. Perhaps survivors did not need to evade responsibility for their scars as the injury/scars may already be perceived as being accidental by others. Implications for the absence of this strategy category will be further explored in the implications section.

Secondly, all of the four patterns used by survivors included the use of the strategy category reducing offensiveness. Typically survivors focused on using the transcendence sub-strategy within this category, which may indicate resiliency on the part of the survivor rather than stigma management. Reasons for this suggestion are explored further in this chapter under the implications section.

Third, similarities were noticed in the types of survivors that populated some of the stigma management patterns. For example, while there may be male survivors that fit the Dissembling Challengers pattern, the participants in this study that fit the pattern were all women. As the Dissembling Challengers often reported hiding their scars, concerns with body image seems a likely influence, especially since many of these participants mentioned various concerns with body image throughout their interviews. Additionally, one other strategy pattern had noted similarities. The Situational Adopters were all burned as children except for one participant. This similarity across the pattern may indicate a comfort with their stigmatizing condition, allowing them to adopt a strategy as needed rather than adopting a specific attitude overall.

Finally, the ways in which stigma was constructed/managed for survivors and partners emerged very differently. Survivors managed stigma in four patterns and partners did so in one. What is important to note is there was no clear co-construction of the stigmatizing communication. When a stigmatizing event occurred, a partner did not try to co-construct it for the survivor. Partners managed stigma for themselves and partners managed stigma for the survivor on their own terms by using denial and ignoring/displaying strategies. This type of construction looked very different from the ways in which survivors and partners work to co-construct sexuality. The next section reviews the findings regarding how survivors and partners co-constructed sexuality.

## **RQ2: Sexuality**

The second research question asked how sexuality was enacted/co-constructed by burn survivors and their romantic partners. The data suggested survivors and their partners co-constructed sexuality in four unique ways: as feeling not sexy, having a fragile sexuality, being a new normal, and not being impacted. Many survivors enacted sexuality as feeling not sexy as a result of struggling with body image post-burn. Sometimes partners would try to counter this not sexy enactment by trying to reconstruct the survivor's sexuality as sexy. Other times, partners would construct their survivor's sexuality as fragile as part of being cautious about the survivor's injury. Additionally, survivors would construct their own sexuality as fragile to protect their own injuries. The new normal was the third way that sexuality was constructed by survivors and their partners. The new normal is an effort to "get used to" the survivor's new body post-burn and the sense of sexuality it entails. Finally, some survivors and relational partners indicated that their sexuality was not impacted by the burn injury.

Sexuality was co-constructed by both survivors and partners. The findings revealed a much clearer co-construction of sexuality than management of stigma. Perhaps it was easier for survivors and partners to co-construct sexuality as they were partners in a sexual activity whereas stigma management can be more challenging when only one individual may be present for a particular stigmatizing event. Partners also may not perceive stigma management to be as paramount as the survivor does, making the co-construction muddy.

While each of the four ways of constructing sexuality is unique, many survivors move among the constructions. For example, the construction of having a fragile sexuality, was usually constructed by partners and survivors early after the burn injury as a way of protecting the survivor from further injury. While it was not specifically stated, survivors and partners seemed to phase this fragile sexuality construction out of their lives after a period of time. Other sexual constructions emerge as more prevalent in participants' experiences as they discussed more recent situations. Many survivors and partners stated the burn injury had no impact while others detailed their sexuality as feeling not sexy. Those reporting feeling not sexy sometimes would also construct sexuality as the new normal. The ways in which survivors moved among these constructions was challenging to pinpoint since the interview protocol did not ask participants to recount their experiences in a chronological order. Future research in this area should focus on the progression of sexuality constructions throughout the survivor's lifetime. This progression may help to pinpoint how survivors move among constructions over time.

Overall, this study is important to scholarly and practical understanding of the stigma and sexuality experiences of burn survivors and their partners. Specific patterns of stigma management communication emerged in the results as participants were engaged in stigmatizing experiences. Patterns of stigma management strategy use were relationally and situationally dependent. Finally, body image played a large role in the construction of sexuality for survivors. In the remaining sections, the following items will be discussed: implications, future directions, practical applications, strengths of the study, and limitations. The next section explores theoretical implications of the study as well as future directions.

### **Theoretical Implications**

The findings in this study have several theoretical implications. Specifically, the results make contributions to Meisenbach's (2010) stigma management communication model and stigma theorizing at large, and have implications for sexuality research. Each contribution is discussed in turn.

#### **Stigma Management Communication**

Stigma management is reflected in burn survivors' behaviors and analyzed using Meisenbach's (2010) stigma management communication model (SMC). Burn survivors' use of stigma management strategies has two general implications for stigma research: development of patterns in stigma strategy usage and a need to focus on the interpersonal context.

**Stigma Strategy Use.** The first major contribution of this project is in its offering and the implications of what SMC strategies are and are not used in various combinations. Though a number of recent publications are discussing this theory (e.g.,

Rains, 2013; Smith, 2012; Smith, 2014; Wright and Rains, 2013) no empirical studies have been published indicating the patterns of actual strategy usage among a particular population. This section addresses the theoretical implications of (a) the strategy that did not emerge within this population, (b) a common strategy across all survivors with potential overlap in resiliency literature, and (c) emerging patterns of stigma management among survivors and partners.

*Evading Responsibility.* The SMC model was used as a sensitizing framework for coding. While the data seemed to be well described by the model, one major strategy category, the evading responsibility category, was not represented in the existing framework. This absence may have occurred because survivors and others may perceive burn scars as accidental injuries rather than something a survivor may be responsible for themselves. This notion supports the results from Kleck and Strenta's (1980) study that argues interpersonal expectancies about behavior can impact the behavior of others. If survivors do not expect others to perceive their injury as their fault, Kleck and Strenta's (1980) study would argue that survivors would not engage in evading responsibility strategies to manage stigma as their expectations would guide others behaviors in how to respond to them.

Perhaps if the survivor did cause the injury, they may engage this type of strategy. While this study did not have any participants who were burned in Methamphetamine (meth) labs, this type of injury may induce an evading responsibility strategy. As meth labs are illegal, the societal stigma of drug abuse coupled with the burn scars may cause a survivor to engage in the evading responsibility strategy. Unfortunately, the current study cannot speak to this possibility since this type of survivor was not present among

the study participants. Future research should investigate survivors burned in situations where blame and/or stigma may be more clearly associated with the activity that led to the burn to investigate potential differences in strategy usage in such cases.

***Reducing Offensiveness.*** A second theoretical implication of the findings stems from how reducing offensiveness was a common strategy category across all four patterns of stigma strategy use by survivors. Specifically, the transcendence sub-strategy was used as a way to reduce offensiveness. However, the extent to which this omnipresent transcendence strategy is a response to a stigma message (Meisenbach, 2010) versus being a method for building resiliency (Williams et al., 2003) was unclear. While survivors are clearly identifying the stigma attribute of having burn scars with a higher purpose in the interview transcripts, which is indicative of the transcendence strategy, it was not always clear that that their statements were meant to combat a stigma encounter in particular. In other words, sometimes they were framing their burn as part of a transcendent experience in general. Perhaps survivors are using the transcendence strategy not as a way of managing stigma but as a method of building resiliency.

Resiliency was defined in chapter two as how an individual uses their coping skills to adapt to traumatic situations such as a burn injury (Williams et al., 2003). Richard mentioned during his interview that the burn community often spoke about “coming to terms with [their] new normal.” The underlying text of this statement speaks to using transcendence as a tool for building resiliency because when Richard speaks about coming to terms with a new normal, he is speaking to survivors about developing their own specific coping skills to find their new normal. Coping is the specific behavior an individual uses to get through a traumatic event (Williams et al., 2003). Resiliency is

then how the survivor uses their coping skills from that point forward (Williams et al., 2003). How each survivor uses these coping mechanisms will vary but demonstrates resiliency when the survivor adapts to their new normal. For example, early in Richard's recovery he said,

It was the worst day of my life, but in many ways it was the best day of my life. I wasn't a dysfunctional shit-bum, but I drank every day. And when I look back on it, it wasn't a good time. It was problem-laden, but it gave me the opportunity to really straighten a lot of things out and look back and reflect on it and open my life to a bunch of good things. And I had a better life my second half of my life than I probably had in the first half.

Richard's statement is clearly a general reflection on his status as a burn survivor rather than him recounting how he managed a specific stigmatizing interaction with another individual. This statement indicated a transcendent moment for Richard; he was demonstrating resiliency. Richard's reflection supports Williams et al.'s (2003) study in which survivors reframed their losses into gains. Reframing loss as a strategy within the Williams study exemplified the concept of resiliency.

Many of the transcendent moments reported throughout the results chapter may have been more indicative of resiliency as opposed to a stigma management strategy. However, just because a transcendent moment does not mention a specific other person or particular stigma message, does not mean the survivor is not managing stigma. In fact, these findings highlight how stigma management may occur from an imagined or generalized other as opposed to a specific situation. What is clear is that transcendent moments occur for each survivor at some point. What remains unclear is how these moments are being used by and function for survivors. Future research should seek to clarify transcendent moments and survivors' goals as they occur and are articulated.

*Patterns of Strategy Use.* The identification of survivors' four clear patterns of SMC is a strong contribution to stigma management theorizing. Currently, no published empirical studies have tested the SMC model, let alone suggested patterns of strategy use. Identification of stigma management patterns within a specified population move stigma theorizing forward by suggesting a linkage among strategies. These linkages need further exploration within the burn community as well as among other stigmatized populations. Future scholars should explore these and others patterns of stigma management among other stigmatized populations.

Within the survivors' patterns of stigma management, there are some interesting trends. When setting aside the ubiquitous use of the reducing offensiveness category from the survivors' patterns, some clear differences emerge between the patterns. Accepters, Dissembling Challengers, and Challengers seem to fit the basic SMC model by remaining on a single side of the chart. Accepters remain on the top half of the chart, always accepting others' perceptions of stigma. Dissembling Challengers stay on the right side of the chart, always challenging the applicability of stigma to self. The Challengers keep to the bottom right corner of the model, always challenging applicability of stigma to self and other's perceptions of stigma. Situational Adapters cross both axes of the model, suggesting other factors beyond their stigma attitudes are at play in strategy selection.

As previously mentioned, the Situational Adopters specified using five distinct strategies to manage stigma based upon the contextual features of the situation. Therefore, the relationship the survivors had with the stigmatizer as well as anyone present during the communicative event may have impacted the strategy used. This data



indicates the importance of the interpersonal context in stigma management. Therefore, the next section discusses the role of interpersonal context within stigma management.

**Interpersonal Context.** Another major implication of this study is that SMC research should consider the role of interpersonal context as part of the stigmatized individual's decision about what strategies to use. Historically, much of the stigma research has been studied as an inter-group phenomena (Hebl, King, Glick, et.al., 2007; Smith, 2012), but few studies have studied how stigma influences interpersonal communication (e.g., Thompson & Seibold, 1978; Smith, 2014). Recently, Smith (2014) took an interest in studying stigma within interpersonal communication by testing her own model of stigma communication (MSC). Smith's study was designed to ask participants about a fictitious acquaintance who had contracted an infectious disease. Her study attended to the interpersonal context through its focus on the perceived dangerousness of an infected acquaintance. Perceived dangerousness of the infected person was found to regulate lifestyle and potential for sharing infection status with others (Smith, 2014). It is difficult to assess how one may react in a hypothetical situation with a fictitious acquaintance. On the other hand, this current project asks participants to recall actual stigmatizing situations in which they interacted with others. The participants discussed stigmatizing situations that occurred one-on-one, in group settings and with close friends, unknown individuals, and acquaintances. Choosing different strategies based on who they were speaking to indicated that interpersonal relationships play a key role when burn survivors determine how to manage stigma.

The findings suggested that survivors were making strategic choices about stigma strategy use based on relational and contextual situations. For example, this finding

emerged as survivors discussed using the avoiding strategy when they hid their burn scars from unfamiliar others while also describing using the ignoring/displaying strategy with their relational partner. Who the survivor was interacting with is therefore argued to have impacted their strategy choice. Similarly, Scott and Stephens (2009) argued that whether and how someone expresses and identifies with a particular target or identity depends on who they are talking to. Scott and Stephens' (2009) argument in identification research parallels the one being made here. Interpersonal relationships play a key role in how survivors manage stigma. Therefore, stigma communication research is advanced by considering the role of the interpersonal context in the management of stigma. How survivors and partners manage the stigma of being burned depends very much on their relationship with the person who is presenting a stigmatizing or potentially stigmatizing message.

The interpersonal relationships a stigmatized individual maintains may impact strategy choices in stigma management, thus complicating the accepting/challenging of a public's understanding of stigma as a predictor of stigma management strategy use. The existing SMC model accounts for the discursive and material realities that may influence the stigma management process overall. In fact, the person the stigmatized individual is speaking to could be considered a material reality. However, the interpersonal relationship appears to be a strong influence on the stigmatized that needs to be separated from other material realities. Therefore, an argument can be made for adding "Interpersonal Relationships" as a moderating variable between the stigmatized individual's attitude and their choice of strategy in the SMC model. As a moderating variable, the interpersonal relationship of the stigmatized individual with the stigmatizer

impacts the strength of the relationship between the stigmatized individual's attitude and their strategy choices. Adding a moderating variable of Interpersonal Relationships to the overall SMC model may give a more accurate reflection of strategy choice. Thus, this project suggests that determining the nature of the relationship of everyone present in the stigmatizing conversation alongside their general stigma attitudes, is essential to successfully determining the stigma management strategy choice. For example, if a survivor normally engages in a denial strategy with strangers but in this instance he was out on a first date, then he might engage in an avoiding strategy to save face in front of his date. He was taking his relationship with his date into account, thereby altering his strategy choice based on his relationship to the person with whom he was interacting.

Meisenbach (2010) organized SMC strategies based upon the proposition that "Individuals will make SMC strategy choices based on their attitude toward the stigma's public applicability to them and on their attitude toward challenging or maintaining others' perceptions of the stigma" (p. 277). The current study did not measure participants' attitudes and as such cannot directly speak to this proposition. However, the fact that Situational Adopters discussed strategies across quadrants challenges the predictive framework offered in Meisenbach 2010. When survivors use either accepting or avoiding coupled with denial strategies, they may be struggling with notions of accepting others' stigmatizing perceptions, yet at the same time challenging them. Therefore, the proposition does not appear to be nuanced enough to capture all of the factors at play in a survivor's stigma management strategy choice. This project suggests that interpersonal context should be added to the model as an additional factor, doing so could strengthen the SMC model overall.

While survivors broke out into exclusive patterns of stigma strategy use, specific strategy use within categories sometimes differentiated across patterns. For example, survivors in the Accepters pattern often used humor as a way to accept stigma whereas those in the Situational Adopters used isolating the self and bonding with stigmatized others as a way of accepting stigma. Other strategy usage across patterns was consistent. In fact, Accepters, Situational Adopters, and Dissembling Challengers all use the avoiding category in the same manner, by hiding the stigma attribute.

Survivors were not the only individuals to have stigmatizing conditions. For example, Jim (partner to Dawn), mentioned having a skin condition called vitiligo which causes discoloration of the skin. The stigmas embodied by relational partners may influence the stigma management process. Therefore future research should investigate multiple stigmas occurring within relationships to determine the impact on the stigma management process.

Finally, having more experience with stigmatization in other areas beyond burn scars may have prepared some survivors in the Challengers pattern for potential stigmatizing situations, thereby influencing strategy choice. For example, Richard mentioned experiencing a courtesy stigma growing up as his sibling had cerebral palsy. Therefore exposure to stigmatizing situations, especially repeated exposure like Richard had, may provide an education of sorts for individuals. This education in stigma may have varying impacts on stigma management choices. Future research should do more intensive investigation into previous and other simultaneous stigmatizing experiences of survivors and how these experiences may impact future stigma strategy use.

**Summary.** Several important theoretical implications emerged from this study that may be applied to the SMC model and stigma literature in general. First, four patterns of stigma strategy use emerged from participant interviews. Patterns of strategy use are a new contribution to the SMC model and stigma research in general as these may spur further investigation into these and others patterns in additional populations. Among all patterns, survivors consistently used the reducing offensiveness strategy. Use of this strategy may overlap with the survivors' attempts at building resiliency. Another constant among the patterns was that survivors changed strategies seemingly based upon their relational connection to the stigmatizer. Therefore, the interpersonal context should be considered when seeking to understand stigma management strategy selection. Furthermore, because some of the survivors used strategies that crossed quadrants, the results challenge the predictive framework of the SMC model. Thus, to strengthen the SMC model, the interpersonal relationship of the stigmatizer with the stigmatized could be added to the SMC model as a moderator between the stigmatized person's attitude and the strategy to be selected. .

### **Sexuality**

In addition to the implications for stigma research, the findings also offer insight into existing research on sexuality. Sexuality was defined for this project as the communicative experience of the intersections among an individual's sexual identity, sexual behavior, sense of intimacy, and relational status (see chapter two). The definition of sexuality created above indicates a social construction of sexuality, thereby making sexuality inherently communicative. As each of the concepts of sexuality is constructed in a cultural context, the ways in which they intersect become unique opportunities for

exploration. This section of the chapter highlights the implications of this study's findings for current research on sexuality and offers suggestions for future research.

**Sexual Behavior.** Many sociobiological theories suggest that men generally initiate sexual activity (LaPlante, McCormick, & Brannigan, 1980; McCormick, 1979). This theory was not supported in the findings of the current study. Many survivors and partners reported that while timing for initial sexual activity post-burn varied from survivor-to-survivor, it was usually initiated by the survivor, regardless of gender. Partners noted that they wanted to wait until the survivor was "ready." The traditional social scripts were abandoned to allow for healing.

Previous research indicated that partners had concerns about survivors' diminished sex drive and performance anxiety and being revolted by the sight of their wounds (Reddish & Blumenfield, 1984). This study extends the Reddish and Blumenfield study by assessing survivors and their partners' sexuality at least six months after the burn injury, whereas Reddish and Blumenfield's study occurred within six months of the burn. An extension of the time frame allows for a larger conceptual picture of a survivor's sexuality. Findings in this study indicated that partners sometimes initially construct the survivor's sexuality as fragile in an effort to protect the survivor from further injury. Neither the partner nor the survivor ever mentioned disgust of the burn injury site.

**Body Image.** Body image is often a challenging concept to measure as it encompasses not only physical appearance, but also body function, competence, sensation, body image investment, resilience, and personality (Pruzinsky, 2004). Furthermore, the subjective nature of the concept makes it hard to talk about body image

when one's very image may change in a given moment or with a specific person (Pruzinsky, 2004). The fluidity of the social construction of body image argues for an interpersonal approach to assessing the intersections of body image and sexuality. As body image is an important predictor in the long term social functioning of survivors (Thombs et al., 2008), an interpersonal approach to understanding survivors' body image concerns would be beneficial. Survivors and partners in this study discussed body image as an important factor in constructing survivors' sexuality.

Findings in this study indicate that those constructing sexuality as not sexy support the theory of self-objectification. This theory states that individuals will perceive themselves as they may appear to others (Fredrickson & Roberts, 1997). Therefore, these survivors think that because they have burn scars, others perceive them as not sexy, thereby constructing themselves as not sexy. Survivors in the not sexy construction also mentioned sometimes being taken out of the moment because they were worried how their scars were being viewed by their partner. This finding supports the concept of spectating, which is being overly aware of one's appearance rather than being absorbed by the sexual activity at hand (Masters & Johnson, 1970).

Parrot and Esmail (2010) argued that survivors with prominent scarring such as on the face struggle with issues of sexuality more often as they don't identify as "normal." However, another study (Thombs et al., 2007) indicated that size and location of the burn scar was not related to the survivor's body image. Furthermore, Thombs et al. (2008) found that female survivors with larger burn sites who placed a greater importance on physical attraction had higher levels of dissatisfaction with body image. Findings from this study may support the Thombs et al. (2008) study as those

constructing their sexuality as not sexy in this project were primarily women. Additionally all but one of the participants had a TBSA over 48%, and all but one of those constructing sexuality as having no impact had a TBSA of lower than 20%. This finding could be read as a trend that size of the burn scar may impact how survivors and partners co-construct sexuality. Such possibilities should be explored in future research. However, size of burn scar alone would not give a full picture of the construction. Body image was a consistent topic brought up by survivors and partners when discussing sexuality. Therefore, body image should be an integral component to the construction of sexuality. This argument supports Parrot and Esmail's (2010) finding that body image may impact a survivor's sexuality. This section of the chapter has explored the implications for sexuality and stigma research of the study. In addition to theoretical implications, there are many practical applications.

### **Practical Applications**

The findings of this study lead to practical applications that may be used to assist survivors, partners, healthcare providers, and the general public. Findings may help everyone understand how survivors and their relational partners find meaning through their experiences in managing stigma and constructing sexuality post-burn. These understandings may help health care professionals offer improved counsel and treatment for survivors and their partners.

Healthcare providers may be the first source of information for survivors and their partners about the potential for stigmatizing communication as they leave the hospital. Therefore, the findings in this study may assist healthcare providers offer survivors and their partners better guidance on how to handle stigmatizing situations based on the



patterns that emerged from the data. Survivors in this study managed stigma using one of four patterns of strategies. Providers may be able to take these patterns of strategy usage and give survivors opportunities to consider their own possible approaches to stigmatizing situations before they encounter a like situation. This tactic may assist survivors in building a healthy approach to stigma strategy use.

While healthcare providers are the first source of information for survivors in many instances, often survivors and partners are hesitant to ask about sexuality concerns due to modesty. Additionally, many providers are uncertain about introducing the topic of sexuality as they don't wish to offend the patient. Therefore, the results of this study should help providers as it details many common concerns related to the sexuality of the survivor. Survivors and their partners constructed sexuality in four ways. These four constructions could be simplified and made into brochures to hand out to new survivors and their partners as potential ways in which their sexuality may be impacted by the burn injury. As brochures are often given out in multiples with others types of information, it would be a nonintrusive way to get information to a survivor or partner without having to risk offending a patient or waiting for the patient to ask.

Healthcare providers are not the only source of information, many survivors and partners seek information on their own using the internet. Using the information from this study, various reputable survivor websites, such as the Phoenix Society (<http://www.phoenix-society.org/>), could report the findings reported here. Specifically, survivors themselves could benefit from seeing specific stigma management strategies and recognizing how they apply to their own behaviors. Perhaps a quiz could be designed from the strategies and examples in the study that other survivors may identify

with. Upon taking the quiz, survivors could recognize which pattern of strategy use they belong to and what that means in terms of how they view stigmatizing situations.

Consideration of the results of the quiz may make survivors aware of other potential approaches and the implications of their current patterns. This new-found awareness may impact or change their approach to stigmatizing conditions for the better.

This study also has practical applications for young survivors and those outside of the burn community. Many survivors who are burned at a young age now qualify for special programs that go into the survivor's school and educate classmates about burn injuries (Phoenix-society, 2011). Understanding how different patterns of stigma strategies are used by survivors can help those who teach others how to respond to survivors. These teachers may be able to construct a tool based on these strategies than can guide students on best practices to aid in seamless re-entry for both survivor and the entire classroom.

Only 14% of surveyed healthcare professionals said they were comfortable talking to a patient about sexuality (Brubaker-Rimmer et al., 2010). Additionally many survivors are too embarrassed to ask their provider about sexuality (Brubaker-Rimmer et al., 2010), opting to research online instead. If websites posted a simpler version of the four constructions of sexuality, survivors and partners would have access to the ways in which sexuality may be impacted by the burn injury. Having a way to view how other survivors and partners construct sexuality should offer some amount of peer support or guidance in terms of sexuality post-burn. This section outlined the practical contributions of the study. The next section discusses the overall strengths of the project.

## **Strengths**

Several strengths contribute to the rigor of the present study. Specifically, the project's overall contribution to interpersonal communication literature, its breadth of participant voices, and its inclusion of partner voices are all discussed in turn as strengths of the project.

### **Contribution to Interpersonal Communication**

A strength of this project is its contribution to the interpersonal communication discipline. Stigma communication research has historically been housed within the health communication (e.g., Kim & Stout, 2010; Smith, 2007a, 2007b, 2012, Smith & Hipper, 2010), organizational communication (e.g., Ashforth & Kreiner, 1999, Ashforth, Kreiner, Clark, & Fugate, 2007; Drew, Mills, & Gassaway, 2007; Tracy & Scott, 2006) and disability literature (e.g., Braithwaite, 1991; Thompson, 1982; Thompson & Seibold, 1978). This study's argument for the consideration of the interpersonal context as a contributing factor in determining strategy use is significant for the field of interpersonal communication. Stigma has traditionally been studied as an inter-group phenomenon. However, adding the interpersonal context offers a new standpoint for viewing stigma communication.

Additionally, much of the research in burn survivor literature and stigma communication is quantitative. Therefore this project contributes to interpersonal communication by giving voice to burn survivors and their partners through qualitative research. Furthermore, the project does not just focus on either group in isolation, this study attempted to gain both survivors and relational partners' experiences, some of which came from couples. This type of data adds to the interpersonal literature in that

one can begin to perceive how co-constructions are being developed or avoided among couples. In addition to contributing to interpersonal communication literature, the present study also demonstrated breadth of participants.

### **Breadth of Participants**

A second strength of the project is that it included participants from a variety of gender identities and geographic locations. 70% of all burn survivors are male, therefore; most studies have reflected a male voice (see Reddish & Blumenfield, 1984, Thombs et al., 2008), often minimally representing the female perspective. As this study sought to be more inclusive of the female survivor's voice, just over half of the survivors interviewed in this study were women. Also, participants represented a number of different geographic locations including California, Florida, Georgia, Indiana, North Carolina, Oklahoma, and Pennsylvania. Only around a third of the interviews came from Missouri. This geographic breadth allowed the researcher to avoid reporting lived experiences that may be unique to one geographic area. The breadth of participants, along with the inclusion of relational partners added rigor to the study.

### **Inclusion of Partners**

Along with a breadth of participants, a major strength of this study is the inclusion of partner voices. Much of the literature in burn research is focused on the burn survivor (e.g. Lawrence et al., 2006; Pope et al., 2007; Thombs et al., 2008) and very little is known about the partner. This study sought out partner voices to determine the extent to which they co-construct stigma management and sexuality with the survivor. The partner's voice is a part of the survivor's lived experience, and is, therefore, a necessary

and worthy inclusion to this study. This section outlined the strengths of this study. The next section focuses on the limitations.

### **Limitations**

As with most studies, this project had limitations that need to be addressed. Issues with participant variety, overwhelming unemployment themes, and challenges with intimate topics are three limitations that are discussed in this section.

#### **Participant Variety**

While a wide variety of survivors were interviewed for this study, partners were in short supply. Multiple attempts were made to encourage partners to participate. Eventually, the researcher even amended the IRB approval to obtain permission to recruit specifically for partners via craigslist. This study may have been enhanced with a larger number of partner participants. However, early analysis of the partner interview data indicated a more consistent experience than that found among the survivors themselves, leading to ending partner interview data collection after eight interviews. Additionally, while the partners' racial make-up was rather diverse, Asian (n=1), Black (n=1), Hispanic (n=2), Middle Eastern (n=1), White (n=3), the survivors' was more limited with only six Black participants to 13 White. Though this diversity is greater than that found in many studies, recruiting survivors from a wider racial pool could have further enhanced the data.

#### **Unemployment**

Unemployment seems to be a theme across the participants in this study that may be viewed as a limitation. Twelve survivor participants indicated they were out of the paid workforce as either someone who is unemployed, a student, a stay at home mom, or

retired. This theme of unemployment might be a weakness in that could be related to the strategy of recruiting through Craigslist. While not all of the participants that identified as unemployed were reached through Craigslist, the majority of them were. The status of being unemployed may have impacted how the participants engaged in stigma management and/or perceived their sexuality, but it may not have had any impact at all. The fact that so many participants identified as unemployed should be noted as a potential limitation since the impact cannot be fully understood. Employment status should also be explored in future research to explore the possibility that burn survivors may be more likely than non burn survivors to be unemployed and to consider its role as a possible additional stigma interacting with burn stigmas.

### **Intimate Topic**

As a final limitation, the nature of the topic required participants to share intimate details of their sexuality and sexual relationships during an interview. During the phase of recruiting through support groups, potential participants who indicated an initial interest in the study, sometimes later backed away from the study because they reported they were not comfortable sharing intimate details. Recruitment of participants was challenging for this very reason. Additionally, men were sometimes more hesitant to discuss intimate details. These men would sometimes engage in hedging or redirecting the statement, or even giving long pauses before responding when they were forthcoming on earlier responses. These behaviors may have impacted the kind of data that was received. Perhaps recruiting a male interviewer or asking participants to journal about their experiences would have eliminated some of the challenges related to the sensitive

nature of the topic. However, as the examples throughout this project show, the people who did participate shared many detailed accounts of these potentially sensitive topics.

### **Validation Strategies**

While two strategies (thick rich description and clarifying researcher bias) were used to validate the study, additional strategies could further enhance the findings. In particular, member checking could be valuable. Member checking involves soliciting participant feedback. The researcher asks a portion of the participants to review the findings to check the credibility of their work (Creswell, 2007; Lindlof & Taylor, 2002). Soliciting feedback from participants could enhance the credibility of the findings for this project.

### **Conclusion**

This dissertation explored lived experiences of burn survivors and their relational partners regarding stigma and sexuality. In terms of stigma management, interviews with 27 participants revealed that survivors have found four unique patterns of stigma strategy management to be valuable while partners primarily use denial strategies. Across the patterns, it was clear that the interpersonal context was important to strategy selection. In addition, survivors and partners move among four co-constructions of sexuality. Future research should focus on how survivors progress through constructing sexuality as well as clarifying transcendent moments of stigma communication.

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## Appendix A

### Initial Recruitment Script

My name is Candy Noltensmeyer, I am a graduate student in the Department of Communication at the University of Missouri. I am recruiting participants for a study that I am working on that examines the stigma and sexuality experiences of burn survivors and their relational partners. In order to participate, you need to be a burn survivor or a relational partner of a burn survivor. A burn survivor is quite simply an individual who has survived a severe burn injury (i.e., second and third degree burns requiring skin grafts). A relational partner is an individual who is in a long-term romantic relationship with a survivor (i.e., marriage or co-habitation). Survivors and partners must be 18 years of age or older and must have left the hospital for initial treatment of the burn six months to five years ago. I will be conducting interviews that will last approximately 45 minutes to 1 ½ hours, depending on what you have to share. All interviews will be audio taped. Your identity will not be revealed in transcripts, written documents, or verbal presentations of the data. Your participation is voluntary. You may quit at any time and you may refuse to answer any question.

If you and your partner are interested in participating and sharing your experiences regarding stigma and sexuality, please contact me so I can set up interviews with each of you. You may contact me via email, [cjnr4c@mail.missouri.edu](mailto:cjnr4c@mail.missouri.edu) or phone, 417-529-0665, to set up an interview. I would like to complete the interviews by July 15<sup>th</sup>, 2013.

I look forward to hearing from you and learning about your experiences with stigma and sexuality!

## **Appendix B**

### **Craigslist Recruitment Script**

#### **Burn Survivors & Relational Partners Needed for Research Study**

Are you a burn survivor who has survived a severe burn injury (i.e., second and third degree burns requiring skin grafts) or a survivor's romantic partner (in a long-term romantic relationship with a survivor such as marriage or co-habitation)? If so, you may be eligible to participate in a research study that explores survivors' and partners' communicative experiences regarding stigma and intimate challenges encountered post-burn. Participants must be 18 years of age or older and survivors must have left the hospital for initial treatment of the burn at least six months ago. If you qualify for this study or know someone who may qualify please contact Candy Noltensmeyer at [survivors@inboxalias.com](mailto:survivors@inboxalias.com) for more information on how to proceed. This study is being conducted by a researcher in the Department of Communication at the University of Missouri. Those who participate in the study will receive a gift card.

## Appendix C

### Facebook Recruitment Script

My name is Candy Noltensmeyer and I am a burn survivor and a researcher. I am currently collecting information for my dissertation on how burn survivors and their romantic partners communicate. I am interested in developing literature to assist survivors and their partners talk through the stigmatizing and intimate challenges they may encounter post-burn, but first I need to know more about their actual experiences.

In order to participate in this study, you need to be a burn survivor or a romantic partner of a burn survivor. A burn survivor is quite simply an individual who has survived a severe burn injury (i.e., second and third degree burns requiring skin grafts). A romantic partner is an individual who is in a long-term romantic relationship with a survivor (i.e., marriage or co-habitation). Survivors and partners must be 18 years of age or older and must have left the hospital for initial treatment of the burn at least six months ago.

If you qualify for this study or know someone who may qualify for the study please contact me at [cnoltens@yahoo.com](mailto:cnoltens@yahoo.com) for more information on how to proceed. Interviews will be conducted that will last approximately 30-90 minutes, depending on what you have to share. Your identity will not be revealed in transcripts, written documents, or verbal presentations of the data. Your participation is voluntary. You may quit at any time and you may refuse to answer any question. Those who participate in the research will receive a gift card.

Thanks! Candy Noltensmeyer

## Appendix D

### Burn Survivor Interview Protocol

Participant (pseudonym): \_\_\_\_\_

Interview began at: \_\_\_\_\_

Interview ended at: \_\_\_\_\_

Total interview time: \_\_\_\_\_

#### **Questions about the physical burn and self:**

Tell me your burn story.

How were you burned? How severe were your burns? Where are your burns located? From where did they graft the skin? How long were you in the hospital? Did you have rehabilitation after you left the hospital? If so, for how long and what did it entail?

Tell me about your experiences with stereotypes associated with survivors.

What do you tell people when they ask about your scars? What is other's response to your story? How often do people stare at you/your burns? How does it affect you when people stare? What is your response to staring? Do you think survivors are viewed as disabled? Have you resented your burn situation?

What kind of social support do you have? What about your partner? How does this help you move forward, or does it? How do you experience resiliency? Can you tell me about your sex life with your partner? How has it changed post-burn?

Tell me about your sexual identity? How do you experience sexuality? How does your sexuality relate to your status as a burn survivor, or does it? Tell

me about your sexual experiences post burn. How often do you have sex? How satisfied are you with your sexual experiences? How has the sexual experience changed, or has it? Does body image affect your sexuality? What about your partners?

**Questions about the relational partner:**

How has the burn injury impacted your relationship?

How often did your partner visit in the hospital? How did your partner handle your burn experience?

How does your partner handle stigmatizing messages?

What does your partner tell people when they ask about your scars? How does your partner handle others staring behaviors?

How does your partner handle the sexual experience?

How have your partners expectations changed, or have they changed?

## Appendix E

### Relational Partner Interview Protocol

Participant (pseudonym): \_\_\_\_\_

Interview began at: \_\_\_\_\_

Interview ended at: \_\_\_\_\_

Total interview time: \_\_\_\_\_

#### **Questions about the physical burn and self:**

Tell me your partner's burn story.

How were they burned? How severe were their burns? Where are their burns located? From where did they graft the skin? How long were they in the hospital? Did they have rehabilitation after they left the hospital? If so, for how long and what did it entail?

What kind of stigmatizing messages have you received?

What do you tell people when they ask about their scars? What is other's response to your story? How often do people stare at their burns? How does it affect you when people stare? What is your response to staring? Do you think survivors are disabled? How have you resented your partner's burn injury, or have you?

What kind of social support do you have? What about your partner? How does this help you move forward, or does it? How do you experience resiliency? Can you tell me about your sex life with your partner? How has it changed post-burn?



Tell me about your sexual identity. How do you experience sexuality?  
How does your sexuality relate to your partner's status as a burn survivor, or does it? Tell me about your sexual experiences after the burn injury? How often do you have sex? How satisfied are you with your sexual experiences? How has the sexual experience changed, or has it? Does body image affect their sexuality?  
What about your partners??

**Questions about the relational partner:**

How has the burn injury impact your relationship?

How did your partner handle their burn experience?

How does your partner handle stigmatizing messages?

What does your partner tell people when they ask about their scars? How does your partner handle others staring behaviors?

How does your partner handle the sexual experience?

How have your partners expectations changed, or have they?

## VITA

Candy Noltensmeyer was raised on a small family farm in southeast Kansas. One of the first in her family to attend college, Candy graduated from Pittsburg State University (PSU) with a degree in Sociology in 2001. After an inspiring class in communication theory, she decided to continue her education and completed her Master's degree in 2003 at Pittsburg State University in Communication. It was during her tenure at PSU that Candy discovered a love for teaching. After completing her Master's she taught Advertising and Public relations courses for 5 years before deciding to get her doctorate. Candy entered the University of Missouri with an interest in organizational communication, however the pull of interpersonal communication was so strong she switched concentrations. The focus on interpersonal communication using concepts from organizational literature as well as personal interests spurred the present study. Currently Candy is an assistant professor and C3 liberal studies coordinator in the Department of Communication at Western Carolina University.