Struggles of Resiliency:

Women Negotiating Interpersonal Relationality Following Burn Injury

by

Tevya A. Hunter

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Department of Psychology

University of Manitoba

Winnipeg

Abstract

Burn injury is considered a distressing and traumatic injury often leading to psychological disturbances such as depression, anxiety, posttraumatic stress disorder, and body image dissatisfaction. At the same time, the literature also suggests that people demonstrate surprising resiliency when dealing with their burn injury. How women who have experienced burns understand their injury and what it means to them to be a resilient, is largely ignored in the burn literature. This study addressed these shortcomings by exploring narratives from thirteen women, recruited from a regional burn center, who experienced a burn injury of up to 30% of their total body surface area (TBSA). Two interviews were conducted with each participant. The first interview employed a photo elicitation technique whereby photographs taken by the participant of her life with a burn injury were used to elicit stories in the context of the interview. The second interview was conducted using a semi-structured interview schedule developed to investigate experiences and understandings of distress and resiliency. The interview transcripts were analyzed using narrative analysis in order to explore how women constructed stories about distress and resiliency following burn injury. The findings show three main struggles the women faced in negotiating resiliency which all pertained to relational tension, that is, relationships with others. The three struggles of resiliency identified in the study are 1) feeling as though the body was public, 2) deciding how to share their burn experience with others, and 3) accepting support from others while maintaining independence. The findings of this study are discussed in the context of a relational theory named self-silencing which delineates how women behave socially to maintain relationships by inhibiting self-expression. Findings are also discussed relative to current research in the areas of burn injury and resiliency.

Acknowledgments

Dedication

To my family: Pam, John, Quinn, and my partner Joe.

-I would not have been able to achieve this accomplishment without your unwavering belief in my ability and patient support

Table of Contents

List of Tables

Chapter 1: Introduction

Individuals with burn injuries use their bodies to illustrate their stories (Moi, Vindenes, & Gjengedal, 2008); and, it is through developing these stories about injury that individuals come to figure out what their "reality" is and how they, and others, fit into the narrative (Frank, 2009). In this ongoing process, subjective understandings of burn injury emerge. Studying these narratives proves to be a rich mode of knowledge production, offering unique perspectives and creating the opportunity to find meaning in the particular rather than in generalizations (Riessman, 2008). There is extensive literature focusing on objective variables of burn injury and related psychological outcomes which has provided researchers with a solid foundation for understanding the phenomenon. While this quantitative information is important, the voices of those who experience burn injury themselves are largely ignored in the literature. Corry and colleagues (2009) and Sareen and colleagues (2013) emphasized the need for qualitative research in the burn literature in order to enhance our understanding of the diversity in individual experience. This study aims to contribute to the burgeoning literature which integrates the subjective into our understanding of burn injury which is essential to knowledge production in order to develop a comprehensive and well-rounded understanding of a topic.

Burns are traumatic injuries with severe consequences both physically and psychologically. While medical advancement in burn care continues to improve physical aspects of burn recovery, psychological research lags behind. The recovery process of burn injury has been linked with significant psychological disorders, such as depression, anxiety, posttraumatic stress disorder as well as body image disturbances (Lawrence, Fauerbach, & Thombs, 2006; Oster & Sveen, 2014; ter Smitten, de Graaf, & Van Leoy, 2011; Wallace, Lees, and Bernstein, 1987; Wiechman & Patterson, 2004). Although women tend to acquire burns less often than men, women appear to

be at increased risk for psychological dysfunction post burn (Thombs et al., 2007; van Loey, Maas, Faber, & Taal, 2003; Wiechman & Patterson, 2004). This suggests that women may experience and understand burn injury differently than men.

While many studies have reported higher mental health risk for women following burn injury, researchers have largely failed to query why this might be or to address the implications this has for women. In a review of psychosocial burn research, Klinge and colleagues (2009) exposed an underrepresentation of women in this literature, indicating researchers have failed to adequately capture women's unique gendered issues. While most studies include a mixed sample of both men and women, with some examining gender differences based on outcomes, studies that go beyond identifying generic gender differences are lacking. For example, while it has been shown that women are at higher risk for depression following burn injury, it is also important to understand what this means to the women who are depressed and how they make meaning of their experience. The way in which women organize their experiences and convey their stories reveals an important layer to the complex topic of burn injury and requires independent investigation using gender specific research design.

The process of burn injury recovery is also associated with positive outcomes such as an absence of psychopathology, rebirth of the self, finding purpose in life, and psychospiritual growth in samples that included both men and women (Lau & van Niekerk, 2011; Moi et al., 2006; Patterson, Everett, Bombardier, Questad, 1993; Williams, Davey, & Klock-Powell, 2003). These outcomes are associated with the concept of resiliency—a term that is well researched but poorly understood. I explore the nuances of the concept further in Chapter 2 but, in general, resiliency is thought to represent "positive" outcomes following adversity. What most existing definitions of resiliency fail to recognize is that resiliency may be multidimensional or situational

(Windle, 2011). Likewise, in emerging understandings of resiliency, resiliency and distress are not being conceptualized as mutually exclusive concepts but suggest that individuals may experience resiliency along with severe distress (Harvey, 2007).

A conceptualization of resiliency that shifts away from objective measures and binary explanations and focuses rather on the subjective nature of resiliency was implemented for the purpose of the current research. As Lau and van Niekerk (2011) explained, taking such an approach to exploring resiliency, "accommodate[s] for fluidity, variability, and tension of opposites" (p. 1167). That is to say that resiliency is a fluid process which includes a tension created by feeling two different ways about the situation or vacillating between understandings. Walsh (2003) suggested that the resiliency process is about "working through" painful experiences just as, before her, Higgins (1994) suggested resilient adults did not simply "get over" or "bounce back" but "struggled well" through suffering. Similarly, Holaday and McPhearson's (1997) research highlights that resiliency is not an end point, but rather, the process of struggling through an experience. Drawing on these understandings of resiliency, I define resiliency as a process by which an individual struggles with a "tension of opposites" to work through an adversity. Assuming resiliency involves the process of figuring out or negotiating tension, investigating what these tensions are and how individuals "struggle through" their experience after adversity is essential for a better understanding of resiliency. It is this process, as it relates to women who have experienced burn injury, which will be explored in the current study.

As noted above, researchers have begun to investigate positive outcomes following burns but have yet to explore how the process of resiliency might be different for women in the recovery from this traumatic injury (Klinge, Chamberlain, Redden, & King, 2009); which, as

previously mentioned, is likely a different experience as compared to that of men. In an article

based on my master's thesis, I worked with women after burn injury, exploring how they

understood their recovery so to better understand women's' perspective on burn rehabilitation

(Hunter et al., 2013). In contrast to the burn literature which suggests that distress about scars,

depression, anxiety, and posttraumatic stress are prevalent in the burn population, the women in

my previous study emphasized their recovery and, surprisingly, the primary narratives were

predominantly about well-being and how little impact their injuries had on their lives. I also

explored the women's counter-narratives. I use the label "counter-narrative" in my research as it

is at times used in the literature to refer to a competing storyline within a narrative (e.g.,

Hampton, 2004; Lau and van Niekerk, 2011) and not to mean a narrative that stands in

opposition to a dominant cultural narrative (e.g., McKenzie-Mohr & Lafrance, 2014). The

counter-narratives included stories of body dissatisfaction and distress that emerged in nuanced

ways. For example, the women used metaphors and powerful adjectives to describe their

appearance including "haggard", "destroyed", "awful", and "defect[ive]". The women also spoke

about trying to hide their scars with clothing and discussed not wanting to talk about their

injuries. Taken as a whole, the women seemed to have ambivalent stories about their burn

recovery process.

　　In comparing the narratives and counter-narratives, I suggested one possible explanation for

the incongruity, or what I labeled ambivalence, was that the women in the study were, at times,

silencing parts of their experience—parts of their experience that were distressing. This behavior

is akin to the theory of self-silencing, which is a cognitive schema, particularly common with

women, in which one inhibits expression of needs and negative emotions in order to maintain

close relationships (Jack, 1991). Another way to understand these findings might have been as

resiliency narratives. It was difficult to understand whether this duality represented efforts at resiliency in the aftermath of adversity or whether the women were silencing difficult aspects of their experience. In the discussion of my MA thesis, I recommended further research to examine this tension, or ambivalence, in the women's narratives. The current study was proposed to further build on these findings in order to better understand women's unique experience with resiliency following burn injury.

Further exploring the ambivalence in the burn injury experience for women throughout the current study may facilitate a better understanding of distress and resiliency following burn injury. This understanding may help ensure we, as health care professionals, facilitate resiliency, and thus optimal psychological healing, following burn injury. The purpose of this research was to explore what resiliency looks like narratively for women who have experienced burn injury by investigating how women "struggle through" adversity. The specific research objectives were:

1) to understand burn injury recovery through the exploration of women's multiple and varied narratives;

2) to explore areas of tension, or ambivalence, that might represent the resiliency process within these narratives;

3) and to advance the understanding of burn injury rehabilitation by providing a more holistic view of the resiliency process for women.

I aimed to address these goals using two forms of narrative data collection. In the first phase, which employed photo elicitation, female participants were asked to take pictures in their everyday life that reflect their experience with burn injury. Each woman then participated in an individual interview, using the photographs as an interview guide. Although an integral part of the method, the photos themselves were not analyzed and are not included in the thesis; but

rather, the narratives about the photos were analyzed. In phase two, participants took part in a

second individual interview using a semi-structured interview schedule developed based on the

current burn injury literature and completed three psychological self-report questionnaires to be

used to better describe and understand the sample. The second interviews also allowed for

follow-up with participants to revisit parts of the initial interviews that may have been unclear or

missed. All interviews were analyzed using narrative analytic methodology. For the analysis, I

focused on areas of ambivalence or tension in the women's narratives since resiliency is assumed

to be a "tension of opposites."

Chapter 2: Literature Review

Burn Injury

Burn injury is a major cause of permanent bodily harm with over 40,000 emergency room visits and over 2,000 hospitalizations in Canada in 2010 due to burn injury (Parachute, 2015). Although burns are not the most common form of traumatic injury, they are often rated as more severe than other traumatic injuries and require, on average, the longest length of stay in hospital (Canadian Institute for Health Information, 2006). Despite these statistics, burn injury has received relatively little attention from researchers looking at traumatic life events (Fauerbach, Richter, Lawrence, Bryant, & Spence, 2002). This is surprising considering burn injuries rank fifth among major causes of death for both men and women aged 15 to 55 years and result in significant personal and social costs including psychological distress, dramatic changes to the body, high health care costs, disability, and increased mortality (Edwards, Smith, Klick, Magyar-Russell, Haythornthwaite, & Holavanahalli, 2007; Wikehult, Hedlund, Marsenic, Nyman, & Willebrand, 2007).

According to the American Burn Association's (2011) National Burn Repository, women represent 25.6% of the burn population in Canada with scald injuries being the most common etiology. The same database suggests women are most often burned in the home, have a slightly higher mortality rate as compared to men, and face distinct challenges following this trauma. For instance, women have been found to be at greater risk for psychological distress following burn injury including higher vulnerability to PTSD, depression, general anxiety, social anxiety, sexual dysfunction and dissatisfaction, diminished health-related quality of life, amputation, and longer hospitalization as compared to men (Dyster-Aas, Willebrand, Wikehult, Gerdin, & Ekselius, 2008; Esselman, Thombs, Magyar-Russell, & Fauerbach, 2006; Summer et al., 2007; Thombs,

Bresnick, & Magyar-Russell, 2006; Thombs et al., 2007; Wiechman & Patterson, 2004).

Additionally, Thombs and colleagues (2008) found women to be far more dissatisfied with their

appearance following burn injury which is in part evidenced by the findings that women

represent 46% of patients receiving reconstructive surgery following burn injury (Thombs et al.,

2007), when they only represent approximately 25% of the entire burn population.

Despite evidence that women and men experience different outcomes following burn

injury, little research explores the genders separately. Earlier research almost exclusively relies

on samples that included both men and women, thus not allowing for an independent

investigation into how women and men might experience burn injury differently. This is

particularly significant from a feminist perspective which highlights differential experiences

between the genders with respect to power, socialization, and health status. For example, many

feminist scholars (e.g., Miller, 1976; Stoppard, 2000; Ussher, 1991) highlight the importance of

political, contextual, and relational factors in considering women's well-being and criticize

traditional models of psychopathology for ignoring political and social variable when

investigating women's health. The traditional models of psychopathology are embedded in

power structures in which the dominant group deems what is valued and normative, requiring the

non-dominant group, in this case women, "to 'fit in,' to 'make do,' with the rules of conduct and

behaviour that may not represent their experience" (Jordan, 2013, p.77). While some studies

delineate distinct differences between men and women with respect to outcomes following

burns, no studies to my knowledge explore the experience of women separately (with the

exception my previous work; Hunter et al., 2013), leaving a large gap in the literature.

Considering the propensity to investigate burn injury using a mixed sample with respect to

gender, the following literature review almost exclusively discusses findings that pertain to both men and women.

Regardless of gender, burn injury is a traumatic assault to the body, leaving individuals in chronic pain, visibly scarred, and at high risk for mental health problems (Fauerbach et al., 2002). However, the emotional needs of patients are often largely ignored and overshadowed given the intense physical implication of burn injury with a major emphasis placed on medical rehabilitation (Wiechman & Patterson, 2004). Psychological stressors following burn injury include exposure to the traumatic event that caused the burn injury, loss of important others in the traumatic event, separation, deprivation, and factors relating to the burn injury itself such as pain, disfigurement, and stigmatization, ("Traumatic burn injury," 2009). Psychological outcomes for both men and women include posttraumatic stress disorder (PTSD), depression, anxiety, and body image dissatisfaction (Wiechman & Patterson, 2004). Specifically, studies report between 13-45% of burn patients suffer from PTSD twelve months post injury, while many more experience subclinical levels (Cakir, Terzi, Abaci, & Aker, 2015; Van Loey & Van Son, 2003). Additionally, the association between depression and burn injury is strong with 20-30% of individuals with burns reporting depressive symptomology (Lawrence, Fauerbach, & Thombs, 2006; Oster & Sveen, 2014). Anxiety is also prevalent in this population with approximately 26% of burn patients experiencing anxiety (Wallace & Lees 1988; Weichman & Patterson, 2004). These statistics should, however, be interpreted with caution as Logsetty and colleagues (in press) did not find a significant difference in new-onset mental health issues among burn injury patients 2 years following injury as compared to a control group. These results suggest that preexisting mental health issues may better explain mental health difficulties following burns. Regardless, psychological issues are particularly important problems to address

in the burn population given the high lifetime and premorbid psychopathology present in this population which may worsen after traumatic injury (Ekeblad, Gerdin, & Oster, 2015; Logsetty et al., in press; Oster & Sveen, 2014; Patterson, et al., 1993). According the American Burn Association (2011), the development of psychological outcomes may not manifest or meet the diagnostic time criteria before patients leave the hospital, however, subclinical or pre-morbid psychopathology may be present and can be addressed immediately.

Considering the psychological consequences of burn injury, it is no surprise that psychological intervention such as cognitive behavioral therapy (CBT), social skills training, supportive counseling, and peer support have been proposed for post-discharge treatment in order to reduce risk of the development of psychopathology (Edwards, Smith, Klick, Magyar-Russell, Haythornthwaite, & Holavanahalli, 2007; Klinge et al., 2009; Wisely, Hoyle, Tarrier, & Edwards, 2007). Wisely and colleagues (2007) found that 63% of burn patients in their sample required supportive counseling or some form of ongoing psychological care to assist with anxiety or depression post discharge. The effectiveness of these interventions, however, is unclear. The few studies that have assessed the effectiveness of psychological interventions in the burn population have produce mixed results although some studies have found the combination of pharmacotherapy and psychotherapy effective for the treatment of PTSD and depression following burns (Katon, Zatzick, Bond, & Williams, 2006; Zatzick, Roy-Byrne, Russo, et al., 2004). For example, a meta-analysis that included ten studies investigating the effectiveness of CBT for preventing chronic PTSD with burn patients found a moderate effect size (Kliem & Kroger, 2013). Such interventions for body image dissatisfaction are less promising. In 2007, Bessell and Moss conducted a systematic review which included twelve studies and concluded there was insufficient evidence to support the effectiveness of

psychosocial interventions for adults with altered appearances; however, these authors suggested that this may be a reflection of methodological issues rather than ineffective interventions and found some promising findings that support the effectiveness of both cognitive behavioral therapy and social skills training. Consistent with these findings, CBT has been found to be effective in dealing with body image dissatisfaction in other populations (Cash & Strachan, 2002). Additionally, a peer support program named Survivors Offering Assistance in Recovery, developed for people who have been burned, has very high patient satisfaction ratings (average rating 6.7 out of 7) but no studies have assessed whether attendance leads to better psychosocial outcomes over non-attendance (Bennett, 2007).

Psychological burn research has traditionally focused on burn severity and location; however, these variables are unable to fully account for the degree of psychological adjustment post injury (Fauerbach et al., 2002). The phrase "small burn, big problem," coined in 1987 emphasizes the impact of burn injury, regardless of severity (Blumfield & Reddish, 1987). Thus, various researchers (e.g., Lawrence et al., 1998) suggest that subjective measures such as interpretations of one's body and importance of appearance are more pertinent in psychological adjustment than objective measures such as the total surface area or depth of burn. The subjective interpretation of the changes to the body following burn injury are particularly significant considering that even after reconstructive surgeries patients often have a non-typical appearance including scarring which leaves skin with darker pigmentation and contours that are raised and irregular (Fauerbach et al., 2002; Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006), in addition to dressings or pressure garments worn, at times, years post injury (Selvaggi, Monstrey, Van Landuyt, Hamdi, & Blondeel, 2005).

Little is known about the course of body image dissatisfaction following burn injury, an appearance altering injury (Lawrence, Fauerbach, Heinberg, et al., 2006). In the research that has been conducted, outcomes suggest that body image dissatisfaction is a pertinent issue with burn patients experiencing body image concerns during rehabilitation despite size and severity of the injury (Lawrence, Fauerbach, Heinberg, & Doctor, 2004; Wallis, Renneberg, Ripper, Germann, Wind, & Jester, 2006). In fact, the subjective measure of body image dissatisfaction is a moderating factor in the development of negative psychological outcomes and was found to be the most salient predictor of psychosocial function, measured using the Short Form-36 Health Survey which is a measure of patient health status, 12 months post burn injury and a substantial variance of depressive symptoms can be explained by body image dissatisfaction in burn patients one year post injury; an association that appeared to particularly pertinent for women. The above cited research emphasizes the importance of considering patients' subjective interpretations of their injuries and how they make meaning of their experience to better understand burn injury.

In the emerging qualitative burn literature, researchers have begun to explore the subjective experience of burn injuries. Many qualitative studies investigating burn injury have primarily focused on how individuals cope with their changed bodies. As Moi and colleagues (2008) point out, a changed body will transform a person's life world. Therefore, the literature offers a window into how peoples' lives change after a burn injury and how they come to terms with this. Of the qualitative research findings relating to the body following burn injury, most were in reference to body appearance, self-concept, and identity. Although these terms are rarely operationally defined, this research seems to be referring to a group of characteristics that are typically stable that define the individual as unique or different from others.

Lau and van Niekerk (2011) as well as Morse and O'Brien (1995) found changes to one's bodily appearance after burn injury led to the "reconstruction" or "regaining" of the self by means of integrating old and new aspects of one's reality into a reformulated self-concept in samples comprised of both men and women. What these authors seem to suggest is that the once stable identity of an individual changes after burn injury or that individuals think of themselves differently –to have a new set of characteristics that make them unique and different. Similarly, a study using phenomenology and grounded theory perspectives found that men and women with burn injuries predominantly spoke about losses and gains to their identity and social roles whereby participants discussed how dealing with situations in which they had a different appearance invoked the need to "reformulate the self" (Williams, et al., 2003). What this group of studies suggests is that individuals develop a new awareness of their bodies after a burn injury which leads to changes in their relationship with their bodies and consequently, their identity.

The burn patients' emphasis on body and identity is not surprising considering how intertwined one's physical appearance, or one's perception of the body, is with one's perception of the self. The shape and appearance of one's body is thought to be central to self-identity, and therefore, the self is thought to be inseparable from the body (Gillespie, 1996; Pugliesi, 1992). Furthermore, the relationship between self-identity and the body is often intensified or brought to light when individuals suffer illness, injury, or disease that may challenge their conceptions of their bodies. In 1987, Zegans claimed that, "the cost of disability is the loss of the unreflective harmony of body" (p.30), meaning that individuals who experience change to their bodies can no longer ignore their bodies or take them for granted but that the body is forced into consciousness. A similar unreflective harmony may be disturbed through appearance changing illness, injury, and disease as a person with a suddenly changed appearance is required to pay more attention to

his or her body considering the perspective that with heightened concern about one's body,

bodily awareness intensifies and profoundly shapes physical self-identity constructs for those

with visible appearance changes (Bernstein, 1990; Fisher, 1986; McLean et al., 2015).

Self-identity from a relational perspective includes our relatedness to others (Jack, 1991),

and posits that there is no self in isolation from others (Mitchell 1988; Radden, 1996). As Frank

(1995) understands it, "the self is understood as coming to be human in relation to others, and the

self can only continue to be human by living for the Other" (p. 15). Thus, from this perspective,

negotiating identity following burn injury would involve considering one's connectedness, or

relationality, to other people. This may be particularly pertinent for women as several different

psychological paradigms understand women to be more relationally oriented, meaning women's

identity and emotional activity often revolves around relationships (Gilligan 1982; Jack, 1991;

Miller, 1976).

Another emerging theme relating to the body in the existing burn literature is the concept

of disembodiment following burn injury. A study by Moi, Indenes, and Gjengedal (2008) found

that feelings of the body being foreign or of being disembodied were common in a sample

comprised of both men and women. Similarly, another qualitative study found that, following

burn injuries, individuals used depersonalized language when speaking of their injuries which

was interpreted as disembodiment (Morse & Mitcham, 1998). The authors suggested that

disembodying language following burns is used to relinquish parts of their bodies during extreme

pain in order to cope.

Individuals, including both men and women, who have experienced burn injury also

appear to be concerned directly with their physical appearance of their body (McLean et al.,

2015). In one qualitative study of women and men, participants expressed concern with the way

their burn scars looked, both to themselves and how others saw them. In a similar study which

analyzed online support group discussions revealed a major preoccupation with scar appearance

and management, which included physical as well as emotional coping related to scarring

(Mirivel, & Thombre, 2010). This research suggests that both men and women struggled with the

meaning of beauty in their contemplation about what *real* beauty is and how inner beauty fits

into their conception of who they are today. The authors of this study point out that, following a

burn injury, people must simultaneously navigate cultural meanings of beauty while developing

their own new interpretations of beauty that may differ from the cultural meanings. Another

similar online study found that both men and women with burn injuries were primarily

concerned with appearance as revealed through their conversations about wound healing,

scarring, and ways to cope with their changed appearance (Badger, Royse, & Moore, 2011).

Furthermore, the participants often spoke of adjusting to having others see their changed bodies.

Mirivel and Thombre (2010) summarized their research with individuals with burns by

suggesting, "concerns about how to best cope with adversity and managing the meaning of one's

bodily appearance lies at the heart of what burn survivors experience daily" (p. 233).

Part of the challenge with respect to body image following burn injury is that patients must

now navigate social situations with a different body and self-concept. As burn patients heal, body

image issues intensify (Thombs et al., 2008). It has been suggested that body image intensifies as

the individual is exposed to the public because this requires them to find a new way to interact in

social situations with a changed body, an altered body image, and others reacting to them

differently (Partridge, 2005). Correspondingly, a prominent challenge in long-term adjustment to

burn injury is difficulty in social functioning including difficulty coping with other people's

behaviour, difficulty directing their own social behaviour, social inhibition, or poor social skills

(Corry, Pruzinsky, & Rumsey, 2009). Studies have found that most adults experience at least temporary difficulties in social or occupational situations post-burn injury and as many as half of them experience chronic and pervasive social strain (Blakeney, Thomas, Holzer, Rose, Berniger, & Meyer, 2005; Rosenberg, Blakeney, Robert, Thomas, Holzer, Meyer, 2006; Taal & Faber, 1998). Social stressors faced by both men and women after a burn include family strain, sexual issues, return to work difficulty, and strained interaction with strangers (Wiechman & Patterson, 2004), while women appear to be at increased risk for developing difficulties in social areas of functions in which others' beliefs, reactions, or attitudes may inform self-concepts such as body image, sexual satisfaction, and self-esteem (Summer et al., 2007; Thombs et al., 2007; Wiechman & Patterson, 2004).

These social stressors represent difficulties with relationality, or negotiating one's relationships with others. These relational difficulties tend to emerge in what Partridge (2005) refers to as the rehabilitation phase of burn recovery, as the individual is discharged from hospital and begins to interact with their social networks and the general public. This stage lasts between 6 months to upwards of 2 years post burn and is characterized by increased body image dissatisfaction, anger, shame, and shifting between pre-burn and post-burn visions of the self in trying to reject or accept an identity as a person with a permanent cosmetic change. In Partridge's (2005) model of burn recovery a final stage occurs where individuals will reject societal norms and adapt new attitudes regarding appearance, facilitating positive adaptation following the injury.

Although social situations can be difficult following burn injury and may contribute to further psychological distress, social aspects also play a role in supporting individuals who have experienced burn injury. For instance, psychosocial adjustment and quality of life factors are

influenced by social involvement and perceived social support (Anzarut, Chen, Shankowsky, & Tredget, 2004; Browne, Byrne, Brown, et al., 1985; Davidson, Bowden, Tholen, James, & Feller, 1981). Additionally, positive effects of stable social relationships have been found the correlate with better adjustment following burn injury (Kildal, 2003; Patterson, Ptacek, Cromes, Fauerbach, & Engrav, 2000), while life satisfaction following burn injury has been shown to be associated with family satisfaction and being married (Hernandez et al., 2014). In a phenomenological study of individuals with facial burns, changes to interpersonal relationships, particularly with respect to feeling more connected to others, was identified as an emergent theme in the participants' narratives (McLean et al., 2015). Further emphasizing the importance of other people's role in recovery following burn injury, severity of burn injury and time since injury are not as strongly predictive of adjustment as are social factors (Browne et al., 1985). Considering women generally orient towards relationships, these factors may be particularly pertinent for this group.

Resiliency

Despite the aforementioned consequences of burn injury, it is important to remember that, in fact, only a minority of people who experience trauma actually develop severe long-lasting psychological symptoms (Ballendger et al., 2004). Therefore, it appears that the typical path following trauma is recovery and that resiliency may be a common phenomenon following adversity (Yehuda, 2004). Women in particular have been shown to be more likely to experience resiliency both in the general population (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996) and in the burn injury population (Rosenbach & Renneberg, 2008), as compared to men.

What resiliency actually means and how it is measured, however, varies greatly within the literature. Since resiliency has been studied in the social sciences, it has gained complexity,

controversy, and a large literature base that lacks clarity and congruence. This has led to a great deal of variance and debate in the literature in terms of how resiliency is or should be defined, conceptualized, and studied (Harrop, Addis, Elliot, & Williams, 2006). There is a plethora of definitions for resiliency including such ideas as "bouncing back to go on with life" (e.g., Netuveli, Wiggins, Montgomery, Hildon, & Blane, 2008; Turner, 2001), "positive adaptation" (e.g., Rutter, 1990; Garmezy, 1993), and "adapting well in the face of adversity" (Margalit, 2004). Although these definitions are all seemingly intuitive, they lack formal definition and direction regarding what terms such as "bouncing back" and "adaptive" actually mean or how we might measure and study this concept. Further complicating the literature is a concept commonly associated with resiliency called post-traumatic growth (PTG) which was defined by Tedeschi & Calhoun (1995) as a "positive psychological experience" as a result of struggling with highly challenging life circumstance. Some researchers conceptualize PTG to be the same as resiliency while others understand the two as distinct concepts (Askay & Magyar-Russell, 2009). Some studies using the definition of PTG to investigate positive outcomes following adversity are included in this literature review.

Psychiatry and psychology traditionally understood resiliency as overcoming stress or adversity in terms of resistance to psychosocial risk (Nigg, Nikolas, Friderici, Park, & Zucker, 2007; Rutter, 1999). Resiliency research in these fields focused on the absence of clinical diagnoses or psychiatric problems over time following exposure to trauma or adversity (Goldstein & Brooks, 2005). Within this framework, resiliency and vulnerability are at opposite ends of a continuum and the general conceptualization is that an individual falls at one of these ends; he or she is either resilient or not. These fields have also generated a long list of factors identified in the existing literature that have been shown to promote resiliency; for instance, the

absence of sexual abuse in childhood appears to be a protective factor against adversity later in life (Collishaw, Pickles, Messer, Rutter, Shearer, & Maughan, 2007). Many researchers have questioned the utility of such research considering the ample evidence to support a seemingly limitless number of factors that correlate with resiliency. Others argue that the resiliency literature base is too focused in individual factors, not taking into consideration context or structural factors, and highlight a need to explore underlying processes of resiliency (Harrop et al., 2006). Researchers thus moved away from identifying correlates and started considering broader contexts.

The biopsychosocial model of resiliency is an example of how resiliency was re-conceptualized as a process (Goldstein & Brooks, 2005). According to the biopsychosocial model, originally developed by Engel (1981), resiliency is a process which takes into account various biological, psychological, and social factors. Each of these factors is thought to have multidirectional influences on an individual which contribute to one's level of functioning over time. This model is one of the most common models used in current resiliency research. For example, Connor and Davidson (2003) understand resiliency as a "stress coping ability" and propose a 5-factor model of resiliency. Factors, which interact and result in varying levels of resiliency, include: 1) personal competence, high standards, and tenacity, 2) trust in one's instincts, tolerance of negative affect, and strengthening effects of stress, 3) positive acceptance of change and secure relationships, 4) control, and 5) spiritual influence. Their model is consistent with Richardson's (2002) model of resiliency which suggests resiliency is the ability to maintain or return to a certain level of biopsychospiritual balance following a disruption in one's base-level of balance.

Broadly speaking, three general models of resiliency have emerged in the literature: compensatory, protective, and challenge models, which all attempt to explain how promotive factors impact exposure to risk. Promotive factors include what Fergus and Zimmerman (2005) label assets, which are positive attributes within the individual, and resources, which are considered outside factors such as parental support or community programs. In a succinct review of resiliency theory, Zimmerman (2013) describes the three models which are summarized here. A compensatory model of resiliency suggests promotive factors work independently to promote resiliency by "counteracting" the effect of risk (e.g., Zimmerman, Steinman, & Rowe, 1998). In contrast, protective models of resiliency suggests promotive factors moderate or reduce to impact of risk by modifying the relationship between risk, promotive factors, and outcome (e.g., Hurd & Zimmerman, 2010). And finally, the challenge model of resiliency, put forth by Rutter in 1987, suggests that exposure to risk works to "inoculate" an individual, making subsequent exposure to risk less detrimental. In other words, if an individual can learn, through incremental exposure to risk, how to manage adversity, he or she will become more resilient.

Although these three general models present resiliency as a process by including an explanation how multiple variables contribute to resiliency or mitigate risk, they fail to provide insight into what the process looks like or how one might engage with the "promotive factors" to build resiliency. The investigation into the process of resiliency, as opposed to identifying promotive factors that lead to positive outcomes or protect against risk, is limited. While many models of resiliency label resiliency as a process, most fail to fully explain what that process entails beyond identifying key contributors. For example, while the biopsychosocial model of resiliency posits that there are several factors (biological, psychological, and social) that have a multidirectional influence on one's level of resiliency, it fails to fully describe the process with

respect to what each factor entails for the individual engaged in building resiliency. Again, we

are left with a more complex understanding of the many variables that either help or hinder an

individual following trauma but we are lacking an understanding of how the individuals

understands or engages with the process of resiliency due to the limits of understanding

resiliency as an outcome and the paucity of qualitative research in the field.

One theory of resiliency that provides some insight into the actual process of resiliency is

based on relational-cultural theory (RCT; Miller, 1976) which focuses the importance of

relationships for healing, growth, and resiliency. RCT posits that resiliency in not an individual

trait but rather lies in the capacity for connection in relationships (Jordan, 2013). The theory

delineates five experiential components of mutually empathic and growth-fostering relationships

that contribute to resiliency in order to provide a better understanding of the process, or what

happens in relationships, to facilitate growth and healing. The components, labeled by Miller

(1986) as the "five good things" are:

1. Each person feels a greater sense of zest (vitality, energy)
2. Each person feels more able to act and does act in the world
3. Each person has a more accurate picture of her/himself and the other person(s)
4. Each person feels a greater sense of worth
5. Each person feels more connected to other persons and exhibits a greater motivation to connect with other people beyond those in one's primary relationships.

Relational-cultural theory is grounded in a feminist perspective suggesting resiliency develops

and is displayed differently in men and women. Jordan (2013) explains that approaching

resiliency from a gendered perspective is essential considering the significant role power and

control—two topics that are largely ignored in mainstream resiliency research—have in exposure

to risk and development of resiliency. For example, she suggests that members of marginalized

or non-dominant groups, such as women, may rely on more relational or emotion-focused and

"externalized" coping strategies since they have less power to effect change. This theory is

discussed here not only to highlight the importance of gender in this research but also as an example of how we can better describe the process of resiliency in order to extrapolate on the plethora of research that has already identified promotive factors.

A major difficulty in the understanding of resiliency is that it is often conceptualized as a static state that is separate from distress in that an individual is either resilient or not; they undergo the process of developing resiliency, or they do not; they have the resiliency trait or they do not. What these definitions fail to recognize is that resiliency may be multidimensional or situational (Windle, 2011). One could imagine that an individual who has faced a significant trauma, such as a burn injury, may demonstrate resiliency in one area of her life and not in another. For instance, it is plausible that she may excel at her job, be liked by colleagues, and obtain promotions while at the same time she may suffer from insomnia and panic attacks as a result of her injury. In this example, would we describe her as resilient or as vulnerable, as adaptive or maladaptive? While it is not uncommon for women to be considered pathological or vulnerable with strengths minimized (Comstock et al., 2008; Jordan, 2002), this conundrum nonetheless led to a shift in the conceptualization of resiliency as researchers began to conceptualize resiliency as a multidimensional construct in which resiliency can co-occur with severe distress (Harvey, 2007). That is, people can be simultaneously suffering and surviving; psychological symptoms and recovery can occur concurrently.

From this adjustment in understanding, a conceptualization of resiliency that shifted away from static and binary explanations and focused rather on the subjectively defined nature of resiliency that takes into account fluidity and multidimensionality emerged in poststructuralist discourse (Lau & Niekerk, 2011), which is a philosophy that values plurality of meaning, suggests concepts are unstable, and critiques the idea that the "truth" can be discovered ("A

Reader's Guide to the Social Sciences," 2001). Approaching resiliency from this perspective allowed for understandings of the concept that encompass what Lau and van Niekerk (2011) refer to as, "a tension of opposites," highlighting that the experience of resiliency also includes its opposite—distress. This understanding allows for feeling two different ways about one's circumstance or vacillating between understandings of one's experience.

Other authors working from this perspective suggest individuals do not simply "get over" or "bounce back" after adversity but rather discuss resiliency as an ongoing process that involves "working through" or "struggling well" through painful experiences (Higgins, 1994; Walsh, 2003). Based on this poststructuralist approach to resiliency, as Holaday and McPhearson's (1997) research highlighted, resiliency is not an end point but rather the process of struggling through tensions faced following adversity. This way of approaching resiliency addresses the common problem of confounding resiliency and positive adjustment. As Fergus and Zimmerman (2005) delineate, positive adjustment is one possible outcome of resiliency whereas the *process* [author emphasis added] of overcoming the risk is resiliency. For the purpose of this research I adopted this way of understanding resiliency. Thus, in the current study I am exploring the process of struggling with adversity as opposed to assessing the outcomes or determining whether the participants have "adjusted well" or "bounced back". This thesis provides an in depth account of what it looks like for women to struggle through burn injury recovery.

Resiliency & Burns

As was shown in the general resiliency literature, individuals who experience burn injury typically adjust rather well following this adversity with an overall perceived quality of life comparable to that of the general population (Moi, Wentzel-Larsen, Salemark, Wahl, & Hanestad, 2006). In 1993, following a comprehensive review of the literature on the

psychological effects of burn injury, Patterson and colleagues concluded by saying, "we are impressed with the emotional resiliency that many people seem to show after suffering this form of trauma" and suggested that burn researchers expand their scope beyond the deficit model of burn injury to incorporate these resilient outcomes. Almost twenty years later, in 2009, Askay and Magyar-Russell commented that despite advancement in the area of growth after trauma, the field of psychological burn research has virtually ignored resiliency with respect to the presence of positive outcomes or the experience of growth after burns. This problem is particularly pronounced with the adult population because most research with both burn injury and resiliency is done with children and adolescents. If the primary path following adversity is resiliency, it seems logical that we need to know more about this process.

The few studies that have addressed the issue of resiliency following burn injuries provide a preliminary understanding of the process. Some qualitative burn research has explored positive aspects of burn recovery which include findings that show men and women redefining beauty, realizing physical strengths, and learning to accept the injury to reduce suffering (Lau & van Niekerk, 2011; Williams et al., 2003). One study in particular explored resilient elements in narratives from a sample of both men and women which included themes rebirth of the self, finding purpose in life, and psychospiritual growth (Lau & van Niekerk, 2011). Holaday and McPhearson (1997) reviewed the literature and attempted to categorize the factors cited as contributing to resiliency and then conducted interviews with individuals who had experienced burn injury. They concluded that factors that stimulate and sustain resiliency include: social support (cultural influences, community, school, and familial support), cognitive skills (intelligence, coping style, personal control, and assignment of meaning), and psychological

resources which referred personality characteristics or dispositional attributes such as internal

locus of control, empathy and curiosity, and a tendency to seek novel experiences.

Rosenbach & Renneberg (2008) investigated posttraumatic growth (PTG) in adults with

burn injury measured by appreciation of life, enhancement of personal relationships, and greater

sense of personal growth. They found that active coping style, social support, and female gender

were the strongest predictors of PTG while burn severity, absence of distress, and quality of life

were not associated with PTG. They also reported that their sample experienced a high degree of

PTG while also reporting high levels of distress and lower quality of life. Holaday and

McPhearson (1997) found similar results reporting that many of their participants with burn

injuries struggled daily as a consequence of their burn and never achieved the life they had pre-

injury but still conceptualized themselves as resilient. That is, the participants with burn injuries

did not understand resiliency as an end point but rather a continuous effort that is a normal part

of their lives. Similarly, two separate studies by my research group that explored narrative from

men and women independently found that both men and women told optimistic narratives about

doing well while also telling counter-narratives that suggested distress and difficulty following

burns (Hunter et al., 2013; Thakrar et al., 2015). The pattern of experiencing distress and

resiliency simultaneously has been identified in other fields of research as it has been suggested

that many individuals deemed resilient continue to experience social, physical, and psychological

problems (Farber & Egeland, 1987; Luthar & Zigler, 1991). This understanding of resiliency is,

however, not well researched, particularly from a gendered perspective.

Significance

In summary, although women experience burn injury less frequently than men, they have

an increased chance of experiencing the negative outcomes associated with this trauma such as

PTSD, general anxiety, social anxiety, sexual dysfunction and dissatisfaction, diminished health-related quality of life, and body image dissatisfaction (Dyster-Aas, Willebrand, Wikehult, Gerdin, & Ekselius, 2008; Esselman, Thombs, Magyar-Russell, & Fauerbach, 2006; Summer et al., 2007; Thombs, Bresnick, & Magyar-Russell, 2006; Thombs et al., 2007; van Loey, Maas, Faber, & Taal, 2003; Wiechman & Patterson, 2004). Thus, we know that there are differences between outcomes for men and women; however, what remains largely unaddressed in the literature is *how* women might approach, experience, or understand burn injury differently in such a way that would account for the gender difference evidenced in previous research. In order to begin to address this shortcoming, women's narratives must be explored independently.

Interestingly, in addition to experiencing higher risk following burn injury, women have also been shown to more frequently experience positive outcomes such as posttraumatic growth following burn injury as compared to their male counterparts (Rosenbach & Renneberg, 2008), once again suggesting that men and women experience burn injury differently. While it may appear counterintuitive that women can be both at increased risk for negative outcomes and have an increased propensity for positive outcomes, these findings may not be confounding when one considers the most recent conceptualization of resiliency which suggests distress and resiliency co-occur (Harvey, 2007).

Positive outcomes and the absence of psychopathology is in fact a common occurrence following burn injury and a majority of individuals who experience trauma do not develop severe long-lasting psychological symptoms (Ballendger, Davidson, Lecrubier, Nutt, Marshall, Nemeroff, et al., 2004). While we have a good understanding of what factors contribute to positive outcomes or mitigate risk, the literature is less developed with respect to describing the process of resiliency—the process that helps one achieve positive outcomes. For example, if

supportive relationships correlate with positive outcomes following adversity, what do those relationships look like, what happens within those relationships, and how does the individual experience those relationships. Qualitative studies have begun to explore the topic of resiliency following burn injury using samples that include both men and women combined and have identified themes such as redefining beauty, realizing physical strengths, learning to accept the injury to reduce suffering, the rebirth of the self, finding purpose in life, and psychospiritual growth (Lau & van Niekerk, 2011; Williams et al., 2003), which help us begin to better understand the process. While these studies offer important perspectives, how gender might influence significant themes of resiliency following burn injury is virtually ignored in earlier research.

This thesis contributes to our current understanding of burn injury by introducing a gendered perspective. As highlighted above, the voice of women who have experienced burn injury is lacking in both the resiliency and burn injury literature. I responded to this shortcoming in the literature by exploring women's narratives of burn injury, focusing on tensions of opposites, in order to target resiliency. This work is important because learning from women directly about what resiliency looks like provides us with a better understanding of this under researched population. Giving voice to women's narratives, not only in the context of burn injury but in any area of inquiry, is vital. From a feminist perspective, women have struggled to be heard and, as a subordinate group, they are often silenced or told their reality is deficient or deviant (Jordan, 2013). Perhaps as a consequence of this, and because some stories are given privilege based on power structures of society (Adams, 2008; Ehrlich & King, 1994; Frank, 1995), there is often a lack appropriate master or cultural narratives for women to draw on to understand their experiences (McKenzie-Mohr & Lafrance, 2011). Thus, women may be

constrained psychologically when it comes to addressing trauma. Through a narrative analysis

approach, the current research moves beyond reductionist understandings of burn injury and

resiliency by incorporating the nuanced and subjective perspective of the individuals that have

direct experience with the topic. This allows for a more comprehensive, profound, and thorough

understanding of the two complex issues of burn injury and resiliency from a gendered

perspective and contributes to better describing the concept of resiliency as a process, rather than

an outcome.

Chapter 3: Conceptual Framework, Methodology, & Methods

Conceptual Framework

This study is a qualitative research project informed by social constructivism, which posits that subjective meanings are negotiated socially and historically and, "emphasize diverse local worlds, multiple realities, and complexities of particular worlds, views, and actions" (Creswell, 2007, p.65). That is to say, using a social constructivism framework, it is assumed that people attempt to understand their world and, in doing so, develop interpretations of their experiences and create meaning regarding events, objects, and people. The main assumptions underlying this study is that there are many influences that contribute to the production of narratives, that not all women are the same, and that the participants will all have unique stories. Therefore, the aim of this type of research is not to uncover the absolute truth but rather to unearth the multiple viewpoints regarding a topic to develop a complex, in-depth understanding of the issue.

I employed a qualitative research design because, in general, qualitative methods are best suited to research conducted within the social constructivism framework as the design allows participants the opportunity to form meaning of a situation and construct comprehensive narratives in response. This type of research design provides rich and descriptive data allowing for the thorough exploration of the research topic. I am using this framework to explore the participants' subjective understanding of burn injury, for which the participants have direct experience, in order to demonstrate the complexity of the topic and gain deeper insight into the phenomenon. In line with a constructivist paradigm, which posits there are multiple subjective realities, the goal of this research is to accumulate multiple and varied narratives in order to provide insight into the complicated experience of resiliency following burn injury.

Within the social constructivism framework, my research is also being approached with a gendered lens. This research project purposefully includes only women because from a constructivist point of view, there are social constructions that impact men and women differently; therefore, men and women will experience and understand the world, and thus burn injury, differently. Some researchers question the validity of findings regarding gender differences in mental health research based on methodological and theoretical issues and suggest that results exaggerate the difference between men and women (Hammarstrom & Annandale, 2012; Pugliesi, 1992). This may be the case, particularly regarding studies that investigate biological differences, however, there are undeniable social differences which contribute to gender differences and continue to impact health (Hammerarstrom & Annandale, 2012). As culture exists today, women and men continue to be categorized and valued based on gender; the disadvantaged position and lower status of women in society affects levels of stress, cognitive styles, and self-esteem, and rates of distress among women (Andermann, 2010; Pugliesi, 1992). As Chan (2009) points out, around the world, "…girls and women are still unable to reach their full potential because of persistent health, social, and gender inequalities..." It is, unfortunately, because of these inequalities that research must explore issues pertaining to men and women separately (Vanwesenbeeck, 2009). In fact, there is a developing literature referred to as "gender-specific medicine" which is dedicated to investigating how men and women differ in the experience of disease (Legato, 2004).

A gendered approach to research is supported by many feminist scholars who argue that research has failed to consider the importance of contextual and relational factors that impact women (Comstock et al., 2008; Robb, 2006), leading to conclusions that pathologize the individual and lead to misunderstanding important contributors of mental health. For example,

one way in which gender may affect one's experience of illness is explained by women's

tendency to have a relational "bias" in thinking (Gilligan, 1982). This is to say that women tend

to be more oriented towards relationships and thus prioritize relational aspects in decision

making. It is argued that the relational bias may be developed as women are socialized to be

empathic nurturers, placing emphasis on maintaining connected relationships (Jack, 1991). This

orientation towards relationship is further engrained by current cultural discourse about

femininity which emphasizes women's "natural" propensity for caregiving and discourages

attention to one's own needs (Jacques & Radtke, 2012; Lafrance & Stoppard, 2006; Stoppard,

2000).

        Women's socialization in this respect can be viewed as detrimental or potentially harmful

to women as the attributes that are encouraged in women are, at the same time, devalued by

traditional models of well-being that emphasize autonomy, separation, and individuation

(Comstock et al., 2008; Gilligan, 1982; Jack, 1991; Miller, 1976). Furthermore, it has been

shown that given this socialization, women may value relationship over the self which may lead

to silencing the self, or suppressing their own wants, needs, and emotions in order to maintain

relationships (Jack, 1991). Self-silencing as a relational mode has continued to been shown as

relevant cross-culturally (see Jack & Ali, 2010) and in a variety of contexts such as physical

disease (DeMarco, 2010; Eaker & Kelly-Hayes, 2010; Medved, 2010), relationships (Neves &

Nogueira, 2010; Woods, 2010), depression (Jack, 1991; Jack, 1999; Mauthner, 2010; Stoppard,

2010), and eating disorders (Geller, Srikameswaran, & Cassin, 2010).

        Despite potentially harmful effects, women may come to consider relational aspects when

attempting to understand the world, make meaning, and negotiate important ideas such as self-

identity. Since meaning-making and self-identity have been found to be central tasks individuals

engage in following injury (Bernstein, 1990; Fisher, 1986; Frank, 2009), from a gendered

perspective, relationality may be important to consider while exploring the women's narratives.

However, to do so effectively, women's narratives must be separated out and examined

independently from men's narratives or important contextual and relational aspects pertinent to

women may be overlooked.

I must address my use of the word "gender" instead of "sex" throughout this thesis. It has

been long accepted that sex refers to biology while gender refers to a social construct (Connell,

2003). Gender, from this perspective refers to, "the socially constructed roles and relationships,

personality traits, attitudes, behaviours, values, relative power, and influence that society ascribes

to the two sexes on a differential basis" (Rieder, 2006, p.7). I chose to use the words associated

with gender (gender, women, men) instead of words consistent with the biological concepts of

sex (sex, female, male) because I am using a social constructivist framework and am exploring

gendered concepts such as body image, identity, and relationality; thus, it is more appropriate to

approach this topic using the concept of gender.

I do acknowledge that the concept of biological sex can be deconstructed and considered a

social construction as well (Butler, 1990). With increased recognition of transgender and

intersected individuals, the artificial binary of female and male is being seriously questioned (van

Ommen & van Deventer, 2011). Labeling a body as male or female is simply another way to

describe the body based on prescribed cultural expectations, which again are socially

constructed. Therefore, there is no "pure body" or no body that is not marked or constructed by

society (Chanter, 2000). Considering this development in gender/sex research, it would be

equally correct for me to use the word "sex" in my gendered research. I argue that the use of

"gender" is more common place in the literature cited in this paper and will thus continue to use

the word "gender" and the related word "women." My intention is that when I discuss gender or

women, I am referring to a social construction of the concept and not a biological distinction.

That being said, I wish to include in my research individuals who identify themselves as women,

as it is the social or cultural experience of being a woman with a burn injury that I wish to

explore.

Narrative Research

Narration is required in all aspects of life as narratives produce realities which help

people make meaning of an experience by highlighting certain elements to create a story (Frank,

2009). Narrative construction is a process especially important in coming to terms with the

experience of illness because it requires individuals to figure out what their narrative of that

illness will be and how they, and others, fit into the story (Frank, 2009). As Medved and

Brockmeier (2008) explain, individuals turn to narrative during illness and disability because,

"narrative is the language of meaning" (p. 1168). Research focusing on illness narratives

emphasizes the importance of patients' speech as integral in understanding the course of illness

or injury (Hyden, 1997). Through exploring participants' stories in this study, versions of

realities are realized and subjective perceptions of burn injury experience emerge. As individuals

communicate their experience with burns, we are able to see how they make meaning of their

experience, how they construct their self-concept, and how they come to understand their

experience. This point is well made by Frank (1995) when he notes that narratives from those

who have suffered illness or injury "give voice to an experience that medicine cannot describe"

(p. 18). Examining how women interpret and understand their burn injury experience through

personal narratives allows for a richer understanding of healing after a burn injury.

A review of the literature highlights how medicalized burn research is with a propensity towards the use of clinical language. This use of language tends to result in a vague, stereotypical understanding of the phenomenon with little appreciation for the subjective understanding of burn injury. While the large body of research examining quantitative aspects of burn injury provides us with a rudimentary, albeit important, understanding of the main issues relating to burn injury, it fails to provide the other side of the story. The existing literature does not adequately address what burn injury means to those who experience this type of injury. Narrative methods are most often employed when investigating meanings individuals construct regarding specific experiences, and thus, narrative research is generally better suited for exploring such nuanced components of an experience like burn injury (Lau & van Niekerk, 2011). The goal of this study was to better understand resiliency after burn injury from the participants' perspective as opposed to uncovering the absolute truth about resiliency; thus, a narrative approach was considered the most appropriate method. This study employed two main forms of data collection, individual interviews and photo elicitation interviews, both of which result in participants creating narratives about their experience. It is these narratives—the stories the participants construct— that are the focus of the current study.

I not only collected narratives as data, but also analyzed the data using narrative analysis (other disciplines use different terms to refer to this method of analysis such as "narrative inquiry"). Narrative analysis borrows from other qualitative approaches such as thematic (e.g., Guest, MacQueen, & Namey, 2012), content (e.g., Krippendorff, 2012) and discourse analysis (e.g., Jorgensen & Phillips, 2002) and is one of many types of qualitative research that analyzes narratives. In an attempt to define and distinguish narrative research from other qualitative

research that uses narratives, Kirkman (2002) outlined four features typical of the narrative

approach in psychology which includes the recognition of:

> 1) the individual person, 2) the subjective dimension of lives and the importance of meaning, 3) the contribution of context to meaning, and 4) the collaborative construction of autobiographical accounts (p.33)

Broadly speaking, what distinguishes narrative research from other methods that analyze

narratives is the focus on the whole narrative account, rather than fragmented parts divided by

discursive units or thematic categories (Josselson, 2011a). Researchers that use narrative analysis

argue that in order to understand meaning making, the whole account must be considered

because parts of an experience do not signify human life nor do they fully represent the lived

experience. As Josselson (2011b) points out, narrative research is concerned with both what is

said and what is not said while also taking into consideration context. She posits, thus, that the

researcher reorganizes, recontextualizes, and creates a new interpretation of the raw data that is

multilayered and may move beyond what the interviewee intended to communicate. The use of

narrative analysis therefore allows us to take a holistic view of experience and consider both

what is being said and how it is being told.

There are various different methods used to analyze narrative data using narrative

analysis. Riessman's (2008) narrative methodology was the main guiding analytic framework

employed for this study. This approach, which is described in more detail later in this chapter,

approaches narratives using three different types of analysis: thematic, structural, and

performative. Because narrative analysis allows for multiple ways of approaching the data and

does not require the researcher to fragment the narrative, allowing for a well-rounded and

comprehensive understanding of the data, it is particularly useful for capturing complications,

dualities, and counter-stories. Hence, narrative analysis is an ideal method to employ in order to

accomplish one of the main objectives of the study which was to develop a more holistic and comprehensive understanding of resiliency following burn injury. Capturing counter-narratives and dualities was specifically important for this study as my focus was on tensions of opposites and identifying ambivalence within participants' overall narratives.

Narratives offer a rich set of data allowing the researcher to explore subjective understandings of a research topic in order to provide a deeper understanding of the issue. Narrative construction processes allow individuals to organize their thinking and give meaning to their experiences (Badger, Royse, & Moore, 2011; Mirivel, & Thombre, 2010). Narrative as an analytic procedure does not simply summarize the stories told by participants and does not posit that narratives "speak for themselves" but that narratives require interpretation by the researcher (Wells, 2011). It is through exploring narratives that we can begin to understand another's world; a world that, from a narrative perspective, is relational and shaped by, "a larger socio-cultural matrix of our being-in-the-world" (Smith & Sparks, 2008, p. 6). Furthermore, narrative analysis assumes storytelling is not merely a cognitive exercise but that it is also a social action, impacted by culture. It was important to use a methodology that allowed for cultural consideration since I am exploring burn injury from a gendered, and thus highly cultural, perspective.

The role of the narrative researcher differs from that of the traditional scientist. Researchers in narrative research are immersed and intertwined in the research process as opposed to being an "outside observer." As Bruner (1990) explains, meaning making is understood from both the participant's narrative and the explicit linkages the researcher makes between understanding and interpretation. This means then, that meaning is co-constructed by the researcher and the participant (Josselson, 2011a). Information gained through the participants' stories is re-storied by the researcher through an integration of the participants'

views and the researchers view into a collaborative narrative (Clandinin & Connely, 2000).

Because of the intimate connection the researcher has with the data, reflexivity, described further

in the research rigour section, was an important part of the research design and was incorporated

into the analysis of the data.

   Photo elicitation. Traditionally in narrative research, researchers use semi-structured

interviews to encourage participants to share their story—to create a narrative. This method has

proven successful in a variety of studies in health psychology such as, chronic illness (Docherty

& McColl, 2003), stroke rehabilitation (Medved, 2011), and spinal cord injuries (Smith &

Sparks, 2004), and was employed in this study as well. A complementary method aimed at

producing narratives, bourgeoning in the social sciences, is a visual research tool called photo

elicitation. Like narrative research, visual tools have been largely ignored in psychological

literature (Harrison, 2002). Visual research tools, most popular in anthropology and sociology,

include such mediums as painting, drawing, video, film, and still photography (Harper, 2002).

The paucity of visual methods in social science research is surprising given how inundated our

social worlds have become with visual images (Harrison, 2002). There are two branches of

visual research; one uses visuals as the topic and one uses visuals as a resource to elicit data.

This study used photos as a resource, which means I used the photographs to elicit stories about

burn injury recovery by translating the meaning of the visuals into words, as opposed to studying

or interpreting the visuals themselves (Chaplin, 1994). Photographs in this type of research are

"mere tools" and may be understood as a mediator in an interview that facilitates conversation,

generates expression, and prompts recollections (Lachal et al., 2012).

   There is a multitude of methodologies that use visuals as a resource. For the purpose of

this study, I employed a method called photo elicitation—a technique described in most detail by

Harper (1986, 1987, 1993, 2000, and 2002). The term photo elicitation was first documented in 1957 by a research team investigating mental health and the environmental basis of psychological stress in East coast provinces in Canada (Harper, 2002). Photo elicitation involves asking participants to interpret images and produce narratives about the meaning they assign to their photos which is thought to facilitate their meaning-making process (Harrison, 2002). Photos used in photo elicitation studies may be produced by the researcher prior to data collection, may be the participant's photos created prior to research, or may be captured by researcher or participant during the process of data collection (Harper 2002). This study used images produced by participants during the research process to generate discussion and, thus, narrative production, in the context of an individual interview once photographs are developed. The purpose of self-generated photographs is to capture the participants' understanding of their experience in order to gain an insider's perspective on the meaning of the research topic. Researchers employing photo elicitation techniques suggest this type of data enables researchers to gain a more direct understanding of the participant's life as compared to data collected solely by the researcher (Lorenz, 2011; Rich, Lamola, Gordon, & Chalfen, 2000).

Photo elicitation is a unique and innovative methodology. Harper (2002), a proponent of visual research techniques, suggests that photo elicitation not only elicits more information from participants but that the process evokes a different kind of information. He suggests that because the parts of our brain responsible for processing visual information are older, evolutionarily, that visual images will "evoke deeper elements of human consciousness than do words." In essence, photographs, given their particular form, will draw for information that may not be realized using only words or narratives. Furthermore, photo elicitation makes the taken-for-granted visible, capturing nuances in the experience that may go unnoticed otherwise (Allen, 2011).

Although photo elicitation lends itself well to a wide variety of research areas, it is becoming popular with researchers in health and illness fields as may argue that photos reveal unfamiliar experiences of health (Harrison, 2002). In fact, photovoice, a specific photo elicitation technique, was developed in the health domain for a study investigating women's health in China (Wang & Burris, 1997). Other topics within health and illness that have been studied using photo elicitation include chronic pain (Baker & Wang, 2006), brain injury (Lorenz, 2011), learning disabilities (Booth & Booth, 2003), stroke (Levin et al., 2007), and breast cancer (Lopez, Eng, Randall-David, & Robinson, 2005). These studies all explore how individuals are marked by illness and how they make meaning of their illness through the exploration of photographs which visually represent their experience.

The inclusion of photo elicitation in this narrative research project was purposeful. Photo elicitation is based on the premise that photos not only facilitate verbalization but that they pull for story-telling. For example, Hagedorn (1994) argued that in her study of families caring for a child with a chronic illness, that the photos "provided symbols of experience that represented the meaning of that experience and prompted spontaneous story telling"(as cited in Harrison, 2002, p.865). Eliciting stories is essential to this study design as stories are the foundation of narrative analysis (Albright, Duggan, & Epstein, 2008). A story, in the narrative sense, is a "first-person oral telling or retelling of events related to the personal or social experiences of an individual" (Ollerenshaw & Creswell, 2002). Therefore, narrative analysis aims to "re-story" stories told by participants, in order to understand their lived experience (Clandinin & Conelly, 2000). Considering photo elicitation interviews result in stories, narrative analytic methodology was germane in this context.

I employed narrative analytic techniques to explore narratives produced via both photo elicitation and semi-structured interviews in what some may consider a mixed methods study. Although mixed-methods or mixed-research designs typically refer to the combination of qualitative and quantitative data sets (Creswell, 2014; Sandelowski, 2000), this study is mixed methods in that at a procedural level I combined two types of data collection and embedded them within a solely qualitative study. Such a design may be referred to as a concurrent nested study (Creswell, Plano Clark, Gutmann, & Hanson, 2003), which refers to a design in which two approaches are implemented at the same time within one study to corroborate findings. While both techniques prompt storytelling with the goal of understanding the subjective experience of burn injury, it was expected that the two interviews would produce different information, resulting in thick data overall. Photo elicitation interviews were predominantly led by the participant, using the photographs she chose to discuss addressing issues pertinent to her. Although the semi-structured narrative interviews were also geared toward the subjective experience of the participants, they were more structured and designed to include topics relevant to the specific research question of burn injury and resiliency.

Ethical Considerations

Ethical approval was granted by the Health Research Ethics Board at the Bannatyne Campus of the University of Manitoba. Ethical guidelines and procedures outlined by the University of Manitoba were strictly followed. Researchers involved in this project attended the Personal Health Information Act (PHIA) course and signed the PHIA confidentiality pledge, allowing them to conduct research as any hospital belonging to the Winnipeg Regional Health Authority. Participants were required to consent to participation following the informed consent procedure in which details of the study were explained and potential benefits and harms were

identified. All participants were provided an informed consent form (Appendix A). Participation

in this study did not affect patients' treatment or medical condition and had minimal risk for

harm. In fact, prior research indicates that a majority of burn patients find research participation

beneficial (Willebrand, Wikehult, & Ekselius, 2004).

Participants

Thirteen women who had sustained a burn injury were purposefully recruited for

participation in the current study. Because the goal of this research, embedded within a social

constructivism framework, was to accumulate multiple and varied narratives, I recruited women

from differing race/ethnicities, ages, time since injury, education levels, and incomes. This

approach was guided by the assumptions that meanings are negotiated socially and that there are

multiple realities, not one absolute truth to discover. To have met inclusion criterion for

participation, participants had to: 1) identify as female, 2) have a burn injury between 1 and 30 %

total body surface area, 3) have been discharged from the hospital for at least two weeks at the

time of the interview, 4) be 18 years of age or older, 5) speak English fluently, and 6) have no

signs of cognitive impairment.

These inclusion criteria were selected for specific reasons. The time since discharge was

important because once released from the hospital, participants had time to adjust and experience

life with their newly acquired injury and thus had potential for more insight into how their

injuries affected their lives (Partridge, 2005). There was, however, no limit on time since injury

in order to recruit a diverse sample. Moreover, those with a total body surface area (TBSA) of

over 30% were excluded from the study as it has been shown that individuals with burns over

30% have distinct psychological outcomes (Noronha & Faust, 2007) while individuals with 1%

were included as it has been shown that despite size of injury, individuals may experience

adverse psychological outcomes (Lawrence, Fauerbach, Heinberg, & Doctor, 2004; Patterson, Everett, Bombardier, & Questad, 1993; Van Loey & Van Son, 2003; Wallis et al., 2006). Given the aim of the study and the intentional focus on women, men were excluded from participating. Lastly, due to the highly verbal nature of this narrative project, the ability to communicate in English and the absence of cognitive impairments that make verbal communication difficult, were pertinent. Thus, women with cognitive impairments or who are unable to communicate in English were excluded. Participants were given a $20 honorarium in the form of a gift card for each interview in which they participated.

Recruitment

Recruitment took place over the course of nine months using a number of approaches. The main recruitment method took place at the follow-up burn clinic in Manitoba, Canada. The surgeon who conducted follow-up appointments with burn patients identified patients who met inclusion criteria and asked them if they would be willing to be approached about participating in research. If the patient indicated interest, the primary researcher approached the patient immediately and in person following their appointment to explain the study and allow the patient to ask any questions. The script used to discuss the study with participants during recruitment can be found in appendix B. A total of ten potential participants were approached by the primary researcher in this context, eight of whom agreed to participate. Additionally, patients who had previously attended the burn clinic and had provided permission to be contacted about research in general, but who were no longer attending appointments, were contacted via telephone by a member of the clinical burn team. A total of eight women were contacted via phone and four of these women participated in the study. The script used for the initial contact by the member of the clinical burn team is included in appendix B. The last method of recruitment took place at a

local conference for burn survivors. An announcement was made to the general audience

regarding an opportunity for women who experienced burn injury to participate in a PhD-level

research project. The primary researcher was available at the conference to speak to interested

individuals and provide further information. Two women approached the primary researcher at

the conference and both participated in the study. In total, twenty women were approached and

fourteen agreed to participate in the study. One woman dropped out of the study for unknown

reasons after signing consent forms but before completing any interviews.

Recruitment stopped when the primary researcher determined interviews no longer

revealed novel narrative themes, patterns or structures and, thus, that little new information

related to the main aim of this study was emerging. To help the researcher decide when to

terminate recruitment, field notes and notes from the initial readings of transcripts were

consulted. Following the review of ten participants' interviews (both semi-structured and photo

elicitation), it appeared that no new narrative data was being collected; however, three more

participants were recruited to ensure saturation of data was met. A total of thirteen participants

included in this study fell within the proposed recruitment objective, outlined to include between

twelve to fifteen participants. The final termination of recruitment was agreed upon by all other

members of the research team consisting of the PhD thesis committee.

Measures

This study utilized six forms of data collection: self-report questionnaires, a socio-

demographic questionnaire, chart review, field notes, photo elicitation, and semi-structured

narrative interviews. Specifics about the procedure are to follow whereby I met with the

participants three times. The first time I met with a participant was immediately following

successful recruitment (procedure described above), at which time I reviewed and obtained

informed consent and provided further information about the study such as the instruction for the

photo elicitation procedure. I then met with the participant at *Time 2* which involved the photo

elicitation interview and again at *Time 3* which involved the semi-structured interview and the

completion of the three self-report questionnaires. Before further elaborating on the procedure,

will outline the measures used in data collection.

      Self-Report Questionnaires. Three psychological scales, the Kessler Psychological

Distress Scale (K10; Kessler et al., 2002), the Silencing the Self Scale (STSS; Jack, 1991), and

the Connor Davidson Resiliency Scale (CD-RISC; Connor & Davison, 2003) were administered

to gain additional descriptive information about the sample regarding important aspects of burn

recovery identified in the literature such as distress, resiliency, and self-silencing. This data was

not used to determine statistical significance but to provide context for a better descriptive

understanding of the sample.

      The K10 is a ten-item questionnaire developed for use in the primary care setting to yield

global scores of distress based on DSM-IV symptoms of mood and anxiety disorders (Kessler et

al., 2002). Each item on the K10 is ranked on a 5-point Likert scale. Total scores are calculated

and range between 10 and 50. People who score from 20-24 are likely to have a mild mental

disorder. Those with scores between 25 and 29 are likely to have a moderate mental disorder,

while scores above 30 indicate a severe mental disorder. The K10 shows excellent precision as it

has been found to be better than other brief screening measures at discriminating cases of anxiety

and mood disorders (Furukawa, Andrews, Slade, & Kessler, 2002).

      The STSS is a 31-item self-report measure with four subscales developed to measure

behaviours or outwardly expressed dialogues which are inconsistent with inner dialogues

pertaining to the same experience (Jack, 1991). The STSS has *good* to *excellent* reliability and

validity on various psychometric tests (Jack & Dill, 1992). The developers of the scale found full scale internal consistencies of .86, .89, and .94 with three different groups of women. They also found test-re-test coefficients from each group to be .88, .89, and .94.

The CD-RISC is a 25-item self-report scale designed to measure resiliency in community samples of adults that conceptualizes resiliency as a successful stress-coping ability (Connor & Davidson, 2003). The CD-RISC has 5 subscales including 1) personal competence, 2) trust in own intuition, 3) acceptance of change, 4) personal control, and 5) spiritual influences. Items have a 5-point response option ranging from 0 (not at all true) to 4 (true nearly all of the time). The CD- RISC has sound psychometric properties with Cronbach's alpha ranging from 0.89-0.93 and a test-retest reliability intraclass correlation coefficient of 0.877 (Ahern Kiehl, Sole, & Byers, 2006; Gillespie, Chaboyer, & Wallis 2007), suggesting it can effectively distinguish those with lesser and greater resiliency (Connor & Davidson, 2003). Higher scores represent higher levels of resiliency but no cut-off scores have been established.

Socio-demographic information. Socio-demographic information was collected from each participant directly following informed consent. Information such as age, education, employment, socio-economic status, psychiatric history, and cultural background was recorded on the socio-demographic questionnaire (Appendix C).

Chart review. Medical information pertaining to the burn injury, such as size, location, and severity of burn, was collected from the participants' medical charts. This information was also recorded on the socio-demographics questionnaire (Appendix C).

Photo Elicitation. Photo elicitation is a participatory research method that employs photography to enhance the participants' narrative meaning-making process (Harrison, 2002). Participants were given disposable cameras or an SD card to use in their own digital camera and

asked to take pictures in their everyday life that reflect their experience with burn injury.

Participants were asked to choose between five to ten photos they wished to discuss in the

interview in which the photographs were used to elicit dialogue regarding the participants'

understanding of their injury. The role of the interviewer was to encourage the participant to

teach the interviewer about the particular reality which is represented in the photographs (Harper,

1986; Harrison, 2002). Interviews were designed to be unstructured, allowing for the participants

to spontaneously tell stories about their photos; however, further reflection and interpretation of

the images by the participants was encouraged by the interviewer (Hagedorn, 1994). Prompts

used in this interview are provided in appendix D. Photo elicitation was used to facilitate the

collection of narrative data, not photographic data, and thus, the photographs themselves will not

be analyzed or included in the findings sections

Interviews. An in-depth semi-structured interview schedule, developed by the researcher,

was followed to conduct the second interview (Appendix E). The interview schedule was

developed based on the current literature review in the area, the aims of the study, and the

researchers' knowledge of conducting successful qualitative interviews and previous experience

working with the female burn population. Additionally, other health professionals with

knowledge about the burn population and qualitative research (allied health professionals,

students and faculty members) were consulted regarding the development of the interview

schedule. The interview process was emergent, and thus, although questions were outlined, the

interview followed the natural flow of conversation; therefore, additional questions may have

been added or deleted as deemed necessary by the interviewer during the course of each

individual interview. It was the interviewer's goal to keep interruptions and questions to a

minimum so that the participant's story could unfold naturally. The interviewer assumed the

stance of a reflective listener, only rarely interrupting to clarify or to probe for additional

information (Morse & Mitcham, 1998). The general order of questions remained the same to

ensure personal or more emotional questions were later in the interview which allowed for time

to become more comfortable with the interview situations, topic, and interviewer herself;

however, during some interviews, the order was changed to allow for a natural flow to the

interview. For example, in situations where a participant brought up a topic earlier in the

interview than would be expected based on the interview schedule, that topic was explored at

that time.

Field notes. The interviewer took field notes during and after each interview to record

interview environment, participant reactions and presentation, and any non-verbal

communication. Field notes were used to offer contextualization of the interviews during

analysis to promote rigour. At times, information from the field notes was used to provide

examples to support the findings.

Procedure

This study involved data collection at three different time periods. *Time 1* involved

collecting demographic and medical chart information and providing the participant with a

camera immediately following recruitment and informed consent. At *Time 2*, the photo

elicitation interview was conducted in which participants were asked to discuss the photographs

they took depicting their life with a burn injury. At *Time 3*, participants partook in the semi-

structured individual interview and completed three psychological questionnaires. The photo-

elicitation interview was intentionally placed before the semi-structured interview so that the

research-informed semi-structured interview information would not influence the more

spontaneous content expected in the photo elicitation interviews. The primary researcher wanted

to minimize the extent the semi-structured interview influenced the photographs the participants

took or what they spoke about in their photo elicitation interview.

Time 1. Following successful recruitment of a participant, informed consent was

discussed and confirmed. All parts of the study were explained and participants were given the

opportunity to express any concerns and ask any questions. Information such as privacy and

ownership of photos, safety issues when taking pictures, what to take pictures of, and issues

relating to photographic consent was discussed and the participant was provided with a handout

outlining the same information (Appendix F). The participant was then instructed to take pictures

in her daily life that reflected her experience with burn injury. The script for the instructions is

provided in appendix G. Participants had the choice to either be provided with a disposable

camera or an SD card to use in their own digital camera. Participants who chose to use a

disposable camera were instructed to have all their pictures developed, for which they were

financially compensated, and then choose five to ten photos they would like to discuss at the

interview. Participants who chose to use their own digital camera were asked to review their

photographs digitally prior to the interview in order to choose five to ten they would like to

discuss in the interview. Pictures taken with digital cameras were not developed but were

reviewed on a laptop computer screen at the time of the interview. As per hospital regulations,

participants were asked whether their photos could be used in the publication or dissemination of

research findings and, if so, a photography waiver was signed (Appendix H). It was, however,

reiterated to the participant that photographs were not being used as data and would, thus, not be

included in the thesis.

Following these instructions, the photo elicitation interviews were scheduled

approximately one month later ranging from between two to eight weeks, allowing for ample

time for the participant to take photos. A mutually convenient time and date was scheduled with each participant at a site chosen by the participant. Options for interview sites included a conference room at the hospital, an office on the university campus, or at the participant's home.

At the end of this initial contact, the participant's chart was reviewed to collect required demographic and medical data such as burn size, location, and severity. Chart review took place at this time for ease of access; since the participants were recruited at follow-up medical appointments, their charts were available and did not need to be pulled from storage. For participants who were recruited via telephone or burn conference, demographic information was collected from their hospital file or data previously collected by the clinical burn team.

Time 2. The second phase of the study involved the photo elicitation interview. At this scheduled appointment, consent was confirmed and participants were given a $20 gift card honorarium at the outset of the appointment. If the participant signed a photographic waiver, photographs were saved to a USB key (or digitally scanned in the case of hard copy photographs when disposable cameras were used). Interviews, lasting approximately an hour on average (ranging from 30-90 minutes), were conducted and digitally audio-recorded. The five to ten photographs selected by the participant were used to guide the interview. The interviewer asked, "what is the story of this photograph?" for each photo. The interview guide, including follow-up questions and possible probes is included in appendix D. The interviewer took field notes during and after the interview to record interview environment, participant reactions and presentation, and any non-verbal communication. Field notes were used to offer contextualization of the interviews during analysis. Lastly, the participant's interview for phase 3 was scheduled for approximately one month later. A mutually convenient time and date was arranged with each participant at a site chosen by the participant. Once again, options for interview sites included a

conference at a local hospital, an office on a university campus, or at the participant's home.

Nine participants chose to complete the interviews at home while four chose to participate at the

hospital.

Following the interview appointments, interviews were transcribed verbatim.

Transcription was performed by the primary investigator, two undergraduate research volunteers

involved in the primary investigator's research group, and by a paid professional transcriber.

Specific transcription conventions (appendix I) were employed by all persons involved in

transcribing. Pseudonyms were used when referring to individual participants to ensure

anonymity. Additionally, proper names used within narratives were changed as indicated by

asterisks. Thus, the excerpts found throughout the findings section are narratively accurate but

may vary with respect to non-essential factual information. Within the excerpts, where there are

two people dialoguing, participant dialogue is indicated with the letter "P" and interviewer

dialogue with an "I." Participant names provided are pseudonyms.

The preliminary analysis of the transcript took place at this point, following the initial

interview. This involved reading through the transcript and making notes of my initial

impressions and identifying any areas I wished to explore further in the second interview. This

analysis, at times, informed the second individual interview, in that I would follow-up on certain

topics or check my initial analysis with the participant. When transcription was not complete

prior to the second interview, I reviewed the taped interview in order to prepare for the second

interview. All data was stored in a password protected Microsoft Word document and saved on

an encrypted USB key.

Time 3. The final phase of the study involved a semi-structured narrative interview with

each participant and the administration of the three self-report questionnaires. Consent was

confirmed once more and participants were provided with an additional $20 gift card

honorarium. Interviews, lasting approximately an hour but ranging from 30 minutes to 90

minutes, were conducted using the semi-structured interview schedule and were digitally audio-

recorded. Following the interview, the three questionnaires were administered via paper-and-

pencil according to standardized procedure. The interviewer once again took field notes during

and after the interview to record interview environment, participant reactions and presentation,

and any non-verbal communication. Following the interview appointments, audio-recordings

were transcribed verbatim using the method described in Time 2.

Data Analysis

The main data analysis in this study involved narrative analysis of the interview data and

is described below. To reiterate, the photographs taken as part of the photo elicitation interview

were not analyzed as the photographs themselves were not considered to be data. Rather, the

photographs were part of the data collection procedure used to facilitate dialogue to capture

narrative data. For this reason, the photographs are not included in the thesis.

Psychological Measures. Psychological scales were scored according to their respective

scoring guidelines and descriptive data for the sample was calculated (mean scores; standard

deviation). This data was used to provide additional information about the sample and a

summary can be found in the *sample demographics* subsection in the findings. Given the small

sample size, statistical significance of group differences was not considered.

Demographic Data & Chart Review. Demographic and chart information was

transferred into a secured Excel file and descriptive statistics for the sample (means and standard

deviations for age and burn size) were calculated. This information is embedded within the

findings section but not included in a separate graph or chart in order to protect the anonymity of participants.

Interviews. Following interview transcription, transcripts from the photo elicitation and semi-structured interviews were analyzed inductively using narrative methodology. Analysis involved looking at both unique and general characteristics of the narratives. Each individual interview transcript was analyzed based on Riessman's (2008) narrative methods by identifying meaningful segments according to thematic, structural, and performative components. In accordance with Riessman's narrative data analysis approach, described in more detail to follow, thematic analysis focused on the content of the narratives while structural analysis focused on how the narratives are constructed (looking at such things as plotlines, metaphors, and overall narratives). Performative analysis concentrated on why particular stories were told and how the way in which stories were told may impact meaning. While Riessman's approach was used for this study , Wells (2011) and Holstein and Gubrium (2012) offer examples of how other researchers delineate similar approaches looking at the "what," "how," and "why" of narratives. Although these three analytic components are discussed separately, it is important to note that they often overlap and in doing so complement each other. Subsequently, the larger meaning of the combined narratives was interpreted and represented again by focusing on thematic, structural, and performative aspects. The initial interpretations were reanalyzed by rechecking the transcript and then the initial results from each participant were compared and contrasted with the results of each of the other participants. Interpretations were shared with a member of the research team (the primary investigator's research supervisor, Maria Medved) and revised accordingly in enhance rigour.

Thematic analysis. The focus of the thematic analysis was to examine *what* was being said as opposed to *how, why,* or *to whom* (Riessman, 2008). In other words, the focus was on "the act of narrative reports and the moral of the story" (p. 62). Important underlying assumptions were coded and general patterns among all transcripts were identified as thematic categories. Significant excerpts from the interviews were selected to use in the discussion of the data. Interpretations made by the researcher, theoretical viewpoints, and past research were also included in the analysis in order to develop an advanced understanding of a phenomenon, as opposed to offering an explanation of the findings. Particular attention was paid to themes of distress and resiliency as well as narrative threads that highlighted ambivalence.

Structural analysis. Structural analysis extended beyond examining *what* is being said and focused on *the way* in which it was being said (Riessman, 2008). Thus, the way in which the participants used language to narrate and organize their stories was examined. Each interview was examined based on the structure and language of the transcript, and furthermore, by examining more detailed narrative forms, stylistic features, and discursive strategies in the narratives. For example, the structural analysis examined coherence, plotlines, and the use of narrative devices such as metaphors. Specifically, sequences and structural parts of the narrative that reoccur were identified in order to determine the function of a particular segment. This approach allowed for the interpretation of multiple narratives such as dominant, subordinate, cultural, and counter-narratives. In contrast to my previous work, in the current study, I did not distinguish the stories using these typical labels as they suggest one story is dominant over, or more important than, what would be labeled as a subordinate or counter-narrative. What was highlighted, however, were dualities, tensions, and ambivalence, without distinguishing a hierarchical order of relevance.

Performative analysis. The focus of performative analysis was to examine *why* certain narratives were being expressed. According to Riessman (2008) performative analysis examines narratives in terms of relation and interactivity and regards narratives as a performance. That is, this type of analysis focuses on questioning who the audience is, who the narrative is directed at, and why it is being told. She further explains that performative analysis is also concerned with contexts, such as the interview setting, the researcher's influence, and cultural influences. Therefore, overall this method of analysis emphasized the position the narrator took and what the purpose of the story was.

Research Rigour

Narrative research assumes that there are multiple realities and it distinguishes between historical and narrative truth. That is, narrative truth is the construction of an experience through storytelling and is not concerned with factual record of what really happened (Josselson, 2011a). As Frank (1995) explains, "the social scientific notion of reliability –getting the same answer to the same question at different times" does not fit within the context of illness narratives because stories change and flux. Thus, I do not claim the findings in this research as facts or truths that can be proven, predicted, or replicated. This aside, several techniques were implemented to ensure the rigour of this study including reflexivity, the maintenance of an audit trail, negotiated validity, and grounding in examples.

Reflexivity. The role of the researcher in narrative research is not to simply report participants' stories but to disentangle the narratives to access a deeper understanding of personal experience (Gabriel, 2004). The researcher is considered an active participant in all phases of research, particularly data collection and analysis, and must accept their role in creating, analyzing, and understanding the data (Bishop & Shepherd, 2011). With this role, it is assumed

to be impossible to set aside one's perspective, biases, or assumptions while conducting research but important to make this explicit by addressing reflexivity (Elliot, Fischer, & Rennie, 1999). I include here a biographical précis in order to explore my connection to the research topic and discuss my assumptions and biases. It is however important to note that researchers cannot know exactly how and when their own experience, understanding, or biases impact the research process; it is impossible to step out of one's intersubjective world (Bishop & Shepherd, 2011).

   Biographical Précis. I am currently a PhD student in clinical psychology program at a Canadian university. I have completed all of my clinical training and defending this research is the last requirement before obtaining my degree. My interest in traumatic injury began when I began my graduate training and was invited to participate on a large scale study investigating traumatic injury. My research group in particular was responsible for the qualitative portion of the burn injury project. My Master's level research stemmed from this and my research focus has been burn injury, specifically with women, since that time. This means I have been working with women with burn injuries for nearly 8 years. Many of the participants have asked me whether I had experienced burn injury myself. I have not. However, during the time I have been involved in burn research, I spent time at the burn clinic and attended conferences for burn survivors in order to better understand the women with whom I work.

   As my research focus suggest, I have a particular interest in how women experience the world. It is my opinion that within the Western culture, women have not yet achieved equal social value. While I acknowledge there are many contributing factors to the disparity between how men and women experience the world, I believe our diminished social value is a main factor in this difference. I find this to be particularly important in the context of burn injury, where we are focused on the body. I have come to learn the intimate connection women have to their

bodies and the deep value that is placed on the female body, almost as if it is our currency in the

world. My initial interest in burn injury was tied to the body, and how damage to the body

impacts a woman's psychology and relationship with her body. Although the body does not

always emerge as the focus of my papers, I find myself drawn to this aspect of the phenomenon

which invariably impacts my data analysis process.

   I also have clinical experience working with trauma, with the main focus being military

trauma—both physical and psychological. This has recently expanded to include all sorts of

workplace traumas, again both physical and psychological. As part of this work, I have had the

opportunity to work with a small number of clients who have experienced burn injuries. The

overlapping of my clinical and research work has help inform both practices. As I am trained

both as a researcher and a therapist, I find myself analyzing my research data through a

therapeutic lens. As a therapist, one is trained to hear the intended message of what a client is

saying—what are they approaching but not yet ready to say aloud? In therapy and research, I

listen, or read, for the emotion – in addition to the language. That is, I reflect on what the tone or

affect is of the narrative and tend to follow up with questions about emotion during interviewing,

digging deeper for the underlying feelings associated with the story the participants is telling. I

am also trained primarily from a cognitive-behavioural orientation which focuses on the way in

which people think; thus, in my research, I tend to focus on the content of what participants are

saying. Overall, of course, my training impacts how I understand the narratives I analyze in my

research.

   Applying Reflexivity. As explained above, reflexivity, or being mindful with respect how

our own beliefs and values impact our research interpretation of the findings, is pertinent in

qualitative research. I have already shared a general overview of myself and my relevant work in

the areas applicable to this research and to follow, I wish to be explicitly more transparent about how my history and beliefs may have impacted the findings in the present study.

In reflecting on my findings and discussion, I became aware of my own propensity towards Jack's self-silencing theory, the importance of which will become apparent later on in this thesis. I cannot recall exactly when I became aware of this theory but it was sometime during my Master's level training in clinical psychology. My advisor had used this theory in some of her work with health research regarding cardiovascular interventions (e.g. Medved & Piran, 2011). Thus, it most certainly came from her work but I don't know if it was her reflecting or suggesting this theory based on the work I was doing with women with burn injuries or whether I was made aware of this theory from her work and applied it to my own. Regardless, I have been drawn to this theory and integrated it into my work over many years. From a research rigour perspective, I also think I am drawn to this theory because it fits my data. I must also look at personal factors that influence my propensity towards this theory because I cannot remove these personal factors completely when engaging in research. On a personal level, I like the theory because I think it make sense to me in my life, in that I find myself engaging in self-silencing in my relationships and find I tend to take responsibility for the health of my relationships.

As I mentioned throughout this paper, self-silencing was one way I understood my results in my Master's level work with women with burn injuries. That work went through many drafts and revisions and the self-silencing piece got moved, removed, added back in, shrunk, changed, but in the end was included as a way of understanding the ambivalence in the women's narratives about their injuries. I did not begin this research project with self-silencing as the main focus of the research. Although I included the Silencing the Self Scale based on my previous work that suggested this construct may be relevant in the burn population, this scale was a minor

element in the overall study design. The scale was included with the intention of being able to

better describe the sample and was not intended to be a main analytic component. Although this

research was informed by my Master's research and thus to some degree by self-silencing, I did

not intend to "find" self-silencing as a major focus of the women's narratives. In fact, part of me

tried to stay away from it because I did not want to produce another piece of research that was

simply a duplicate of my past research. To take a new perspective, I used the lens of resiliency to

explore burn injury. I wanted to look at what made women strong, how they survived, and even

thrived, following burn injury. As will become clear later in the thesis, the first overarching

theme that stood out during analysis was the influence and importance of other people in the

women's narratives. Others created tension; they were good, they were bad, they were something

to negotiate and to work through after burn injury. However, the more I explored the data, a

second overarching theme emerged when I looked at what these women did with relational

tension. What emerged was what looked like self-silencing. It was not something I looked for but

it was something I could not ignore. Now, had I not been aware of Jack's theory, or if was not

passionate about women's cultural status, or had a previous working theory that self-silencing

was an important part of burn injury, I may not have focused on or revealed this in my data.

Given the assumption I cannot remove myself from the research process, it is not surprising I

came to understand the data in this way.

     Audit Trail. The use of an audit trail in this study was used to enhance the rigour of the

findings by recording methodological and analytic processes and decisions made throughout the

study. Audit trails are deemed essential in qualitative research because of the emergent nature of

this type of research (Sandelowski & Barroso, 2003). The primary purpose of the audit trail is to

allow others to follow the line of reasoning employed for analysis and the rationale for

methodological decisions. I also used the audit trail myself to enhance the rigour of this study by reviewing the trail to ensure logic and cohesion and to apply reflexivity. A review of the audit trail confirms the emergent nature of the analysis. In the beginning of the analysis process other people seemed to be the focus of the women's narrative. I found myself, however, discounting this focus as I felt it would be a disservice to the women who participated in the study. I felt it was my responsibility to tell their story, focus on their experience, and to not talk about others. However, as the analysis progressed, the focus on the other was becoming stronger and harder to move away from. In this, I realized stories about others were in fact still about the women. The women, in their experience, focused on others, emphasized others, included others in their experience. If that is what they narrate, that is how the findings must be presented. As I continued to write in this direction, I became more comfortable, or confident, that others were what the participants found outstanding in their experience of burn injury.

Negotiated Validity. Negotiated validity was used to ensure theoretical validity which is an important dimension of rigour and refers to the extent which the researcher's interpretations and constructions are valid (Maxwell, 1992). Negotiated validity is a collaborative process where the members of the research team discuss the assumptions and orientations which lead to the interpretations (Sandlewoski & Barroso, 2003). An argument must be presented in order to persuade other research members that the analysis is grounded in and fits the data; consensus is based on the most persuasive argument. This process primarily occurred between the author and her research supervisor, having challenged and revised interpretations several times over the course of six months.

Grounding in Examples. Grounding in examples requires researchers to provide adequate examples from the data to illustrate the understandings and interpretations of the data

(Elliott, Fischer, Rennie, 1999). Throughout the findings section, narrative excerpts are provided

to allow the reader to appraise the fit between the data and the author's interpretations while also

allowing the reader to develop his or her own conceptualizations or understanding of the data.

Chapter 4: Findings

Sample Demographics

Below I describe demographic variables for the study sample but I do not include the typical demographic chart in the reporting of my sample as the participants are part of a small community. As such, presenting all demographic information together may render any individual participant identifiable, thus compromising anonymity and confidentiality.

Thirteen women between the ages of 20- and 72-years, with a mean age of 42-years, participated in this study. The size of the burn injuries, measured by TBSA, ranged from 1% to 30% with a mean size of 8%. This sample was a diverse cultural mix with women identifying as Mennonite (2), Aboriginal (2), Metis (1) Canadian (4), South American (1), East Indian (1), and Canadian Ukrainian (2). Five of the women were single at the time of the interviews and eight were in relationships. The education level of the participants ranged from having completed the eleventh grade to having completed a bachelor's degree. With respect to premorbid psychiatric histories, 6 women reported prior mental health conditions including depression, bipolar disorder, anxiety, substance use, and schizophrenia.

The women who participated in this study had experienced their injuries throughout the lifespan with the youngest age of injury being 4-years old and the oldest being 70-years. The mean age at the time of injury was 35-years. The average time since injury was seven years prior to participation in the study and the mode was one year. The location of the injuries varied and included neck, chin, trunk, stomach, arms, legs, genital area, breasts, face, back, and hands. Seven of the women required hospitalization following their injury while six received only emergency medical care. One participant had partial amputation of three fingers as a result of the injury.

Sample Description

Three self-report questionnaires were administered with the purpose of further describing the sample according pertinent aspects of burn recovery. The K10 was administered which is a brief screening questionnaire used to identify the presence of a DSM-IV mental disorder (Kessler et al., 2002); it does not however, distinguish a specific diagnosis and thus represents non-specific psychological distress. According to the K10 questionnaire, over half (61.5%) of the sample were likely to have at least a mild mental disorder at the time of data collection. More specifically, two participants met criteria for *severe* mental disorder, three met criteria for *moderate* mental disorder, three met criteria for *mild* mental disorder, and five participants did not meet criteria for any mental disorder. Table 1 displays descriptive statistics for how many participants fell into each of the five categories of mental health disorders. It is not possible based on the data collected and study design to determine whether the psychological distress reported was a consequence of the burn injury or pre-existing.

Table 2 displays descriptive statistics for both the Silencing the Self Scale (STSS; Jack, 1991) and the Connor Davidson Resiliency Scale (CD-RISC; Connor & Davison, 2003), including comparison group means. Based on data measuring self-reported resiliency obtained from the CD-RISC, 8 out of 13 (61.5%) participants in the current study scored higher than the mean reference score in a sample of acute trauma survivors in Canada (Daniels, 2012). Higher scores represent higher levels of self-reported resiliency. With respect to the STSS this sample scored highest on the *Care as Self-Sacrifice and Silencing the Self* subscales representing higher rates of behaviour consistent with these subscales. This sample's total STSS mean score was below that of both comparison group means. Subscale mean scores were within 1 standard deviation from the female undergraduate comparison group subscale means.

Table 1

Number of Participants in Each Category of Mental Health Based on the Kessler Psychological Distress Scale (K10)

	None	Mild	Moderate	Severe	Total
Number of participants	5	3	3	2	13
Percentage (%)	38.46	23.08	23.08	15.38	100

Table 2

Descriptive Statistics for Silencing the Self Scale (SSTS) Total and Subscales and the Connor Davidson Resiliency Scale (CD-RISC) with Comparison Group Means

Variable	n	Mean	SD	Range	Comparison Group Means	
					Undergraduate Women (Jack & Dill, 1992)	Women in Cardiac Rehab (Medved & Piran, 2011
STSS						
Externalized Self-Perception	13	16	3.39	9-21	18.2	
Care as Self-Sacrifice	13	23	4.61	17-32	24.5	
Silencing the Self	13	20	6.36	10-31	20.6	
Divided Self	13	14	5.04	9-24	15.1	
Total	13	72	12.96	51-101	78.4	87.5
CD-RISC					Trauma survivors (Daniels, 2012)	
Total Resiliency Score	13	73	14.29	49-97	68.9	
Below comparison mean [a]	5 (38.5%)					
Above comparison mean [b]	8 (61.5%)					

Note. Low scores represent lower levels of self-reported resiliency while high scores represent higher levels of self-reported resiliency. [a] Below comparison mean includes scores between 49-67. [b] Above comparison mean includes scores between 68-97.

Overview

As described previously, twenty-six interviews with thirteen women with burn injuries were analyzed using narrative methodology. In this section I present the main findings and offer some preliminary commentary but provide a more detailed analysis of the findings in the discussion section. The themes to follow emerged approximately equally from narratives produced during the photo-elicitation interviews and the semi-structured interviews. For the photo- elicitation portion, the participants took a wide range of photos including photos of significant people in their lives (husbands, children, siblings, grandchildren, friends), where the injury happened (home, restaurant, backyard), objects that were involved in the injury (fire pit, lighter, kettle), the injury itself at various points throughout physical healing, professionals that were important in their recovery (physiotherapist, occupation therapist, reiki master), places or objects that made them happy (home, rainbows), medical supplies used during recovery (garments, ointment, scissors, gauze, pressure mask for the face), as well as objects that represented changes in their lives (clothing used to cover scarring, a bed representing change sexual relationships, pictures of their bodies before the injury, or non-injured parts of their bodies). The most common photographs taken were of family, homes, and the injuries at various time points. As I explore the findings below, at times, I make reference to specific narratives that emerged based on specific photographs.

Just as the photographs had common themes but were diverse, so were the women's narratives. Although the findings are presented in a cohesive and organized manner, the women's experiences were by no means universal. Not every woman struggled with each of the issues explored and the participants were often at different points in the process of negotiating their recovery. This is reflected throughout as ambivalence is highlighted. Overall, however, the

themes discussed were far-reaching in that they emerged in a majority of the interviews and

spanned across age, race, time since injury, and size of injury. While there were many individual

differences amongst the participants' narratives, general storylines are presented and explored to

follow.

Although it was expected that photo elicitation interviews would prompt spontaneous

storytelling, this was not always the case. Participants frequently required prompting and the

interviewer often asked several follow-up questions in order to facilitate narratives during the

photo-elicitation interviews. Rich narratives were collected during both sets of interviews with

no apparent benefit between the data collection methods. However, the two interviews were not

as distinct as they are described in the methods section in that stories told in the first interview

(photo elicitation) were carried over into the second interview. That is, participants would pick

up from topics already discussed in the earlier interview, thus, creating overlap in the content of

the two interviews. Therefore, although a story may have been triggered by a photo taken as part

of the photo elicitation portion of the study, the more developed and detailed narrative may have

actually emerged during the second interview. This may have also been a function of the

participant developing rapport with the interviewer and feeling more comfortable to elaborate

and expand on narratives during the second meeting. Time may have also contributed to

carryover between interviews in that the time elapsed between the two meetings may have

allowed the participant time and space to think more about their stories and develop them in new

ways that were then shared during the second interview.

The aim of this thesis was to explore narratives to better understand how women build

resiliency—defined as the process of struggling through adversity—following burn injury. Thus,

in this chapter I explore narrative threads that highlight tensions between opposites—or

ambivalent understandings—to examine how the women worked through the burn injury experience. The women's stories were mainly organized around themes of relationality whereby the women struggled to negotiate their connection or relation with others in variety of different contexts. That is, relationships with other people following burn injury presented complicated interactions that the women sorted out in order to build resiliency and move forward in their recovery.

The relational tensions explored in this study are divided into three main struggles of resiliency, making up the three subsections of the findings portion of this study.

i.   The first subsection, *The Body Made Public,* looks at how some women struggled with a process whereby the private body became public following their burn injury. This occurred when other people observed, commented on, or asked about the woman's injury which brought the body into focus, typically making the women feel awkward, self-conscious, or uncomfortable. This section also explores the ways in which some women seemed to work against this process by covering their bodies or avoiding others.

ii.   In the second section, *To Share or to Protect,* I explore how some women appeared to struggle to connect with others around their injury through shared experience and storytelling without burdening them. I show in this section how many of the women took on the role as protector in situations where sharing was perceived to be too much for the other person.

iii. And finally, *Accepting Support from Others* is the third section in which I demonstrate how some women negotiated their understanding of what it meant to accept support from others during their recovery. Here, these women seemed to

vacillate between easily accepting support from others while struggling to maintain their independence.

Overall, these findings suggest negotiation of relationality—or how to negotiate one's relation to others—is a significant component of struggling through a burn injury to build resiliency for these women.

The Body Made Public

Burn injury is a physical injury: an assault to the body. It is not surprising then, that one of the struggles many of the women faced in building resiliency involved their changed bodies. Narratives about the body in this study were constructed as highly relational, involving others. That is, the women's relation to other people—family, friends, sexual partners, strangers, and the public—seemed to shape the way most of the women understood their bodies following burn injury. The narratives revealed a process following burn injury whereby the body, which these women appeared to understand as a private and intimate entity, became public or exposed to others. The body was forced into the public arena in several different ways, explored below, including:

    i.   in situations in which the public observed and commented on the changed body,

   ii.   in the context of medical appointments,

  iii.   and during intimate sexual experiences.

In their stories, these women illustrated how they fought against their bodies becoming public— through covering, hiding, and shutting out others—to keep their body private; a body that was being forced into the public arena as an object of discourse and examination, open for comments and observation. Although part of this process involved discourse about the body, the tension emerged not because the women do not want to tell their story but because people focused on the

body solely because of the appearance of the injury. The women seemed to take offense to that

fact the others felt it was reasonable or acceptable to comment on someone's body—particularly

a part of the body that is different, in some way. I illustrate that engaging in this tension—private

versus public—is one pathway to building resiliency.

Some women explicitly articulated how the private body became public following burn

injury using the very words of "private" and "public." Monica, a 26-year-old, explored why

being asked questions about the burn injury on her forearm bothered her. In doing so, she

explained that her body was private ("it's not like it's supposed to be there for everyone to

know") and implied that questions about the injury invaded that privacy.

> P (Monica): Yeah, it's like our bodies are like supposed to be, you know, private like.
> And I don't think, it's not like it's supposed to be there for everyone to know, only if
> you're like really close to me, so when I'm with other people, I don't know why they
> would think that it's okay to ask, you know so.

Here, Monica was perplexed by others' blatant disregard for her privacy when they "think it's

okay to ask" about her body. It is as though the questions about her injury forced what she

believed was private into public discourse and, in doing so, violated her boundaries. In her

second interview, Monica spoke again about her annoyance with others asking questions. Her

frustration was evident when she said, "everyone just thinks it's okay to ask," suggesting that in

fact it is not acceptable to ask but is rather intrusive. Tension was indicated in her narrative when

she suggested that she could not explain her story easily, making it more difficult to relate to

others when asked about the injury. In her fight for resiliency, she resolved the tension created

when others ask about her injury by"[giving] them a tone," indirectly communicating her distaste

and unwillingness to continue with the injury discourse.

Joan, who was burned on her face, scalp, back and neck, also included a story about

others having privileged access to observe what is private in a narrative about going to a

convenience store the day she was discharged from the hospital. In the excerpt below, she

concluded her story about the convenience store by suggesting that she felt exposed because her

burn injury was on her face, a location that was highly visible and not easily covered. Not being

able to cover her body, or more specifically her scarred body, meant that "everybody knows"

which again created a sense of exposure that was unwelcomed and out of Joan's control.

Interestingly, Joan understood her pain as "different" because of the location and its exposure to

the world.

> P (Joan): The pain was so different than I've ever experienced cause it was on my face,
> you know rather than a, a leg I don't, I didn't have a leg burn, it's just on your face so
> everybody knows, so.

Later in her interview, Joan indicated that she continued to avoid being in public after this

incident. Her response to the public versus private tension was to isolate herself. Although

leaving her home was something she found difficult prior to her injury as a result of a preexisting

mental health disorder, her experience on the day of discharge appeared to reinforce her

avoidance of the public following the injury. The two narratives explored above from Joan and

Monica came from women who both had visible injuries (face and forearm), which present

unique recovery consideration (Lawrence et al., 2004). Both women emphasized their discomfort

with strikingly similar structural components in their narratives such as the language about

"everybody knowing." They both seemed to understand their injuries as something they would

like to keep private but that others disrupt that privilege, simply by observing the injury –simply

by "knowing" it is there.

Carrie also clearly articulated a sense of her body becoming public in her narrative she

told that emerged from a photograph she shared of the elementary school that she was attending

at the time of her childhood burn injury. This example also demonstrates how she engaged with

the tension created as her body became exposed by struggling to make meaning of the others

actions as "well-meaning." This particular narrative was about a time she performed at a school

concert and, as she was walking off stage, an adult volunteering at the school commented on her

injury. She began her story by explicitly identifying the public component by saying, "people

think you're public property, okay?" and described a humiliating social incident in which she

was singled out for appearing different. Carrie told a second story in which a woman at the

hospital said, "thank goodness it [the burn] didn't get your face." Carrie explained that although

the woman was "again really well-meaning" she felt "singled out for appearing different or

disfigured." Structurally, the language of being "singled out" highlights the process of the body

coming into focus, of being exposed, through comments from others. In the excerpt below she

described her reaction to situations in which others commented on her injury by first expressing

strong anger but quickly correcting herself to perform a more empathic role towards those that

upset her by explaining they are probably "well-meaning."

> P (Carrie): It pisses me off. ((laughs)) It makes me angry; like how stupid are you? Um, at the same time, I, you know, should be compassionate or understanding knowing that most people have no clue about what it's like to be seriously injured by burn. And that that's a good thing because it's a horrible thing to happen and there's, I wouldn't you know as an adult of course, I don't wish that on anybody. Umm, and you know people I guess they mean well or meant well in their own way, but it's this notion of and again I've certainly read about this in the disability literature this is fairly common, um, kind of seeing the person as less than (2) or whatever just you know, up for public commentary.

Carrie concluded the narrative above just as she introduced it, by underscoring the idea of the

body becoming public. Comments from others, whether they are "well-meaning" or not, invaded

her privacy as her body became "public property" and up for "public commentary." The public

invasion of her body "makes [her] angry" but she seemed to continue to perform what could be

understood as femininity by laughing while telling her story and by diluting her anger through

excusing other people's behavior. Indeed, laughing throughout her two interviews was prominent

and often occurred as she discussed anger —an emotion not typically associated with femininity. In her struggle with the body made public process, Carrie seems to shut down her own anger and forces herself into the empathic, forgiving, relational role when she says, "I *should* (emphasis added) be more compassionate or understanding."

There is a process made evident in the emerging narratives in which comments from others about the women's bodies creates a sense of privacy violation. That is, the body's appearance incited comments from others which then resulted in many of the women feeling uncomfortable, annoyed, or upset. The women in the excerpts explored thus far seemed starkly aware of the process in which their bodies became public following their injuries, using language such as "private" and "public." Other examples of the body becoming public were more nuanced in the narratives but provide further insight into the struggle many of the women grappled with as their bodies became objects of public gaze and commentary. Although the content of the narratives are similar, they are organized differently from a structural standpoint. For example, below, Olivia who had a 1% total body surface area burn to her left forearm a year and a half prior to participating, explained that the only reason she did not want to have permanent scarring was because it would prompt questions from others. Considering how other women spoke about comments and questions from others, we might conclude that Olivia, although not explicitly using "public" or "private" language, is speaking about the same process. The following is Olivia's response to a question about what it is like to have others see her injury.

> P (Olivia): Doesn't bother, no it doesn't. The only thing is, is I really don't wanna have a scar like that for the rest of my life. Like somewhere that is, you know, I'm not a vain type person, but I still don't wanna go through the rest of my life, "oh what happened," that's, you know and. That was kind of eh, where, it was like I am excited to have a sleeve ((therapeutic pressure garment)), cause now nobody's gonna go, "oh what happened to you?" 'Cause that's all I was getting, then it's like, kay, they're still gonna ask that question because the sleeve's still there, right? It was just always having to answer that question

I: Right. So it just got kind of irritating or in a way like kept having to tell the story or
P: And the thing is, um my mother's a more important person and I'll go to banquets with her a lot and to be where I, "oh what happened," or "what happened." And, and it's not one person there that asks you that night, it's twenty people that ask you that night…Yea and it's like kay you know what I'm, I'm done with this ((laughs)) right, so, but yeah.

Sabella shared a very similar narrative as Olivia's, in which she was annoyed with people asking questions about her injury and found people reacted more intensely once they found out it was a burn injury. Although Sabella, like Carrie, understood their reactions as "well-meaning," people's overreaction when telling her story made her uncomfortable. Situations in which others asked questions about the injury required these women to figure out how to handle relationality—or how to interact with the people who made them angry or uncomfortable. Even though these women found comments made by others upsetting, they excused this behaviour as well-meaning. By labeling it as well-meaning, the women then appeared restricted from confronting others on the behavior which could have protected them from the prying of others. Perhaps in an attempt to maintain connectedness, the women remained silent about their discomfort with questions from others.

Some women explicitly mentioned occasions when conversations about their injuries made them feel awkward and stressed. For example, in the excerpt below, Brittany told a story about a man at a bus stop who initiated conversations after seeing her scarring because he had also been burned. Although Brittany understood their injuries as a point of connection, she explained the conversation went too far beyond her boundaries and became a source of stress, rather than comfort. Furthermore, the body being exposed through the act of questioning was constructed as uninvited as Brittany explained it made her uncomfortable, particularly because her injury was in a place on her body that was considered private.

P (Brittany): Where there was a guy at the bus stop, who pointed out right away, 'cause of my graft sites kind of on the side here, and I was wearing a skirt. And he asked if I'd

been burned and he told me he also had, he showed me his arm. But being the area it is, I kinda wished he'd stop talking at that point, because the conversation got very (1) just twisted. And it wasn't even about the burns at that point, it just opened it up where he felt a connection with me with that, but then he was telling me about how he got it, cause his ex-wife had done it to him on purpose, and telling me he killed her after that or something. It was ah (1), so it's situations like that where it creates (1), it's almost harder when it creates something that is the same, where it's a bond or a common thread for people to talk about. That's been (1) awkward. I don't think about it a <u>huge amount</u> or talk about it necessarily with people, unless it's directly brought up. And so to have (.) think about it with that kind of this or have it brought up, where it's stressful almost.

Here Brittany negotiates her relationship with a stranger at the bus stop. At the end of the excerpt, Brittany explained that she does not talk about her injury unless it's "directly brought up," suggesting she only talks about it when others initiates the conversation. She also described talking about the injury as "stressful" which suggests other people were initiating conversations that she found distressing; in fact, she "wished he'd stop talking" at one point. She further suggested that talking about her injury is "almost harder" and "awkward" when people felt connected to her because of shared similar experience. The narrative created a sense of forced intimacy with which Brittany was not comfortable. Again, her body, which Brittany does not think about or talk about "a huge amount," was forced into public discourse. It is, however, more than not wanting to tell her story, which is further addressed in the second findings subsection. Here, it is about her body being commented on and observed. The stranger at the bus stop "pointed out" her injury—he brought it to the forefront of their joint consciousness. She also attributed her body's appearance for the reason he started talking to her when she says, "'cause of my skin graft." A process in which a stranger observed and commented on a body, bringing it into focus, resulted in Brittany feeling "awkward" and "stress[ed]." Despite her conversational partner's shocking revelation he may have killed his ex-wife, Brittany appears to focus on the awkwardness created through the discussion about her burned body. Also important to note here is how Brittany used words such as "almost" several times throughout her narrative, minimizing

the affect evident in the story. She also does not directly confront the intruder but silently wishes

he would stop talking. Once again, the participant politely performs what appears to be a

traditionally feminine role by allowing others to continue while silently feeling distressed.

Although all of these narratives emerge in situations in which other people were able to

observe the women's injured bodies, most of the women presented themselves as less concerned

about the appearance of their bodies but rather upset that their bodies were being brought into

focus through questioning, comments, and discussions. These examples begin to overlap with the

next section where I explore tension that emerges when participants share their burn injury story

with others. The focus now, however, is on the body, not the story. Regardless of *what* is said or

how the woman responded, what is emphasized here is that the body loses its privacy following

burn injury when other people look at, observe, and comment on the body. It is as if the body no

longer belongs to the woman but becomes, perhaps for a brief moment, public—up for

discussion whether warranted, wanted, or welcomed by the woman. Although these women often

minimized the encounters and acknowledged that the comments and questions were benign, the

mere act of asking questions appeared to bother these women. Throughout these narratives, the

women spoke about being "singled out" based on the appearance of their bodies which evoked a

sense of being exposed by others' comments and questions. They constructed questions and

comments from others as invasive and suggested that boundaries were crossed when others

initiated discussion about their injuries—and their bodies—pressuring the women to broach a

topic to which they are not necessarily open. Comments and questions from others seemed to

provoke anger in most of the women specifically when it was obvious that the body's appearance

elicited the comment or question. When comments were triggered by the appearance of the body,

it was as though the body was revealing secrets, privacy was spoiled, and others were privy to

what was considered privileged. Most women, however, did not express dissatisfaction with the appearance of their bodies, but rather dissatisfaction with other people. Thus, it seems that many women had to navigate their own reactions of feeling angry, invaded, or violated, while still maintaining connection with others by minimizing their own anger, excusing the behavior as well-meaning or by "giving a tone." These women did not directly confront others but regulated their own experience, perhaps in an attempt to maintain the relationship.

The privileged body was also exposed in the context of medical apportionments following burn injury. Here, others were constructed as observes of what was once considered private and not for "everyone to know." In the excerpts to follow about the body being exposed in medical appointments, the focus on burn injury specifically seems to fade and rather the entire body comes to attention; this attention is, nonetheless, a result of the injury. The three following excerpts are examples of how women discussed having to reveal their bodies in the context of medical appointments which evoked a sense of exposure and discomfort. Carrie, who spoke above about feeling like public property, also remembered feeling exposed in the context of burn treatment twice during her initial interview in which she included a photograph of the hospital in which she received her medical treatment as a child.

> P (Carrie): Getting, you know, totally- well you're naked on this little gurney thing that they raise up and then lower and lower you into there so you're completely exposed. Then you're in the water and the water's <u>hot</u>. And some nurses were nicer than other nurses in terms of the peeling off the dressings. And this is like a <u>daily</u> event right, and um, yeah.
> ~~~~~~
> P (Carrie): Um, I remember being, you know, like standing up against a wall <u>naked</u> and being, you know, taking pictures of me before and after this or that.

Similarly, Trish, who was burned on her thighs and stomach at the age of 31 years, spoke on several occasions about how uncomfortable she was showing her body. She constructed stories about being naked both in context of the hospital during burn treatment and in daily life

with others with an overriding theme of embarrassment. In the excerpt below, she was so

uncomfortable with showing her naked body that she suspected that without the support of her

boyfriend and having gone through a similar experience during the delivery of her first child, she

likely would not have sought out medical treatment for her burn.

> P (Trish): Yeah, 'cause people want to look at it. Like, "let me see." And it was on my fat
> belly and on my fat thighs and I don't want to show people. It was embarrassing. Like if
> the doctors were guys and I just I already had issues there I-I didn't like having to, it was
> embarrassing.
> I: So even having it treated and that sort of thing wasn't comfortable
> P: No, like if I was younger than what I was now and hadn't lived this long, I don't even
> know if I would have went to any of the appointments. I was like that shy, like very shy.
> I: What made you able to go to the appointments?
> P: I think just like having a boyfriend for a long term relationships and having maybe him
> and maybe having to face the doctors like see me naked and stuff. And having a bunch of
> guys and stuff staring at you and you don't want them to. And you're naked. Like that
> kind of made me go, "ok, if I can go through this, I can do this too."

The prying eye of others was performed in Trish's narrative when she mimics a non-specific

voice saying, "let me see." She goes on to explain that she "already had issues there" (meaning

body image issues), which she suggested made exposing her body to the prying eyes even

harder. She appears more anxious about others seeing her "fat belly and fat thighs" while

revealing her injury than she does about showing her scars. Field notes confirm that Trish was

particularly concerned about body image in general as noted in my initial impressions during the

interview. Her story highlights how some of the women perceived their entire bodies becoming

public following burn injury and introduces an intersection between preexisting body image and

burn injury.

Looking at these examples structurally, all three excerpts emphasize the word "naked,"

constructing nakedness as a shocking and dreadful state. Nakedness is framed as the ultimate

form of exposure –there is nothing left to show, all is bared. Thus, being naked in medical

appointments contributed to the process after burn injury in which the body loses privacy and is

thrust into the public domain. While it might be expected that bodies are revealed in the context of medical appointments, the women constructed narratives about this experience that depicted the process as uncomfortable and even invasive. In the previous examples about others commenting on the burn injury, the injury was the focus of the exposure. Here, in contrast, the entire body was exposed as a consequence of the burn injury. The women were naked, their entire body exposed, because they had a burn injury. These experiences are only one part of a larger process being examined whereby the body becomes public following burn injury in various ways and in different contexts. Medical appointments may be necessary but at the same time contribute overall sense of the body being exposed. As compared to the narratives explored at the beginning of this section, here, the other people in the stories take a less active role in the exposure of the women's bodies in that they are not directly commenting on or highlight the changed body. The stories are, nonetheless, relational in that the women's bodies are being revealed to another person and in doing so become part of a public space. However, in these relational examples, it is difficult to see how they struggled through these unpleasant experiences. They seemed to simply bear the dreaded experience.

Some women also spoke about a sense of body exposure in relation others in the context of sexuality –again in a situation where being naked and revealing the body may be expected. Sexual encounters placed the body in vulnerable positions in which others could observe, comment, and reject. Often the examples did not include another person directly commenting or rejecting, but rather focused on the perceived possibility, or fear, of this happening when engaged intimately with another person. Thus, when in relation to another, some women toiled with their own insecurities surrounding the injury. These women spoke about how their burn injuries limited their sexual involvement due to concerns around the appearance of their scarring.

Limits around sexuality ranged from decreasing the frequency of sexual involvement to choosing to reject intimate relationships altogether. Regardless of their relationship status, the women generally expressed anxiety about how their intimate partners might react to the appearance of their "disfigured" bodies.

Brittany, who was burned as a child, explored relationships as she matured and told a story about one of her first sexual encounters as an adolescent which included nervousness, excitement, and apprehension about her partner's reaction. The physical appearance of the scars from the burn injury became the focus of concern in this narrative about sexuality.

> P (Brittany): That's a picture from my cousin's wedding, and that's my fiancé. And for me again with the appearance thing and having scars, um, I was really nervous when I started dating and sexuality and that kind of thing started to be a thing. As like, how do I bring this up, like what's the reaction going to be. And I remember there was one guy I was kind of seeing, some stuff was probably going further than I was really comfortable with at the time, it was also that exciting sort of thing. And then I was, I was really nervous because like well, were getting along really well, but I don't know like taking my pants off is this going to freak him out, how's he going to respond kind of thing. And so I kind of warned him, like you know I've got scars, and I really didn't know what to say beyond that. It was like I guess, it like well I'm telling you I guess can I just show you, without it being like, ah, we're in the middle of something.

In her narrative, Brittany struggled with what to say to her partner about her scarring. She indicated that she "warned" him about the scars but "didn't know what to say beyond that." Brittany gave the impression that the scars on her body were shocking as they required warning and further suggested that more should have been said, as though an explanation was required. A pressure to reveal the body and its history emerged in Brittany's narrative about sexuality. How this pressure compares to pressure women in general might feel to reveal their bodies, however, is not clear.

Although Brittany expressed some enthusiasm ("that exciting sort of thing"), the overall affect in the narrative was anxious with Brittany appearing self-conscious and unsure of herself.

Based on the structural analysis, inconsistency with respect to her response to her body being observed in different story she had told was identified. That is, in contrast, Brittany also shared a story about her current partner, the fiancé referenced at the beginning of the previous narrative. In what follows, we see Brittany negotiate relationality in two different ways. With her current partner, she talked about what it was like when he touched her scars for the first time, after they attended a local burn conference together. She described touch positively, and explained that it, "feels really good" but emphasized it required a lot of trust. Here, we see Brittany more comfortable with revealing her body but in a context in which she felt in control and with someone she trusted. Interestingly, in the narrative with her current partner as an adult, she pointed out that they did not speak but "just sat and were silent" which came across during the interview as something she considered comforting. Not speaking or explaining drastically contrasts with her earlier story about her discomfort in not knowing what to say in an intimate situation. In comparing the two narratives, the process of struggling to build resiliency is nicely demonstrated. We see in the two stories that the relationship itself, the other person, and perhaps life experience, can change one's construction about sexuality and the body. That is, Brittany appeared to have negotiated relationality differently in the two narratives, first by trying to explain her injury to the other person and then by being silent and allowing the other person to explore her body. The struggle to build resiliency here involved Brittany trying out different ways of interacting with others during sexual encounters which resulted in becoming more comfortable revealing herself to others.

Janice, who was in a committed relationship at the time of her injury, also reported concerns about how her partner would react to her naked body. The relationship she was in at the

time of the injury eventually dissolved and in the excerpt below she explained her fears about

pursing new relationships.

> P (Janice): And, and, and I, it just sort of stays like that um, uh for years it was because of, I was scared of being ju-, like judged or uh you know having, that what, uh my scars and you know things like that I was scared like you know, they were gonna see the scars and be like, "yikes, I'm out of here" you know cau-, I, and I didn't want that, I didn't want that hurt so I allowed myself, I, I didn't allow myself that, and um, and then in the recent years um (2) I'm just really comfortable with what, with the way my life is right now.

Janice explained that she feared being rejected because she believed that anybody that saw her

scarred chest would leave her. As she spoke more about relationships, she revealed that she

initially believed the relationship she was in at the time of the injury ended because she was

"hideously disfigured." Janice later realized, as she mentioned in another part of the interview,

that her reaction to her injury and attitude towards others may have in fact been the cause of the

relationship breakup. For example, she remembered being very angry following her injury which

manifested in being rude and aggressive with others. She also explained that she did not want to

go out or be with other people and therefore intentionally kept others out of her life. Thus, it

appears Janice worked through her burn injury experience to build resiliency and in doing so she

was able to understand that it was not her body, but rather her actions towards her partner and

others, that caused the breakdown or relationship. Despite her revised understanding of the

relationship and its demise, which absolved her body, she continued to struggle with the tension

and chose not to be in relationships. Her perception of potential rejection and hurt based on the

appearance of her body continued to be entrenched in her understanding of intimate relationships

and influence her decision to not pursue them.

Not all the women in the study went as far as avoiding relationships all together but

encountered difficulties when exposing their bodies in intimate situations nonetheless. Sabella,

30-years-old, told a story below about sexuality in a long-term committed relationship. This

excerpt emerged from a photograph Sabella took of her bed, which she explained represented her

sexual life and how it was affected following her burn injury because she started avoiding sex

with her husband. Sabella performed her sadness about the appearance of her body in the context

of sexuality by crying, creating a long pause, as she told the story.

> I: And would you say to this day you feel self-conscious about the scarring (2) with him?
> P (Sabella): Yeah, I guess so. It's much better because the legs, that were like the part
> that were more affected, it got so much better. Some of the scars healed, there is no scars
> actually some of the burns healed completely. Ah, but there are still some so you know,
> um, yeah. Like it it it still feels like, for the same reason that I don't want to wear a shorts
> you know um, it is still like. And I know that he is okay, but it's really like as a woman.
> I: Yeah, what it is, what do you think it is, as a woman that makes it so difficult?
> P: Well I guess because you like, like I guess other women would, but I like to be
> attractive right, and like um so it's kind of like half feeling like you're not as attractive
> anymore ((crying)) Sorry. Sorry. [I: It's okay, it's difficult stuff] Yeah, exactly (5). So I
> think it's feeling not, not feeling as attractive anymore ((through tears)) ah, yeah.

In further discussion about sex following burn injury, Sabella continued to struggle with

the tension as she explained that she was comfortable being naked in front of her husband in

different contexts –getting dressed, for example– but that her discomfort emerged specifically in

intimate situations, when she perceived appearance and attraction to be more important. Thus, it

appears that her own negative beliefs about her body were triggered in relational situations where

importance of appearance was perceived to be heightened. Sabella later reported that her

husband "doesn't care" about the appearance of her scars. However, she explained that *she* is

uncomfortable in sexual situations, regardless of her husband's reactions. Thus, the other person

in this scenario was not directly creating the discomfort—via comments or questions as I

explored earlier—but rather, it seems, like the woman's own beliefs about her body in relation to

others created distress. Similarly, in Janice's narrative, she came to realize that others did not

reject her body but, regardless, she appeared to hold strong beliefs about her body that continued

to impact her relationality with others. Insightfully, Sabella highlighted the gendered aspect the

body in the context of sexuality by pointing out that the body and its appearance may be

particularly important to women. In a sense, women may anticipate rejection based on one's own

feelings about the appearance the body and one's own assessment of how important appearance

is. The insecurity about the appearance of the body appeared to be incited when in relation with

other people but not based on their behaviour. That is to suggest, the process of the body

becoming public—being revealed to others—was uncomfortable, regardless of how the other

person responded.

　　While being naked may be indeed vulnerable for most women, the women in this study

had the additional challenge of revealing a body that is not typical or expected. This required

many of the women to negotiate how to respond to a body becoming public, in a relational world

where women's bodies in general are examined, criticized, and controlled. In other words, being

naked following burn injury prompted a tension in which resiliency was built as the women

struggled through difficult relational experiences in order to figure out how to live in these

contexts.

　　In negotiating the process of the body becoming public, we have seen how most of the

women worked at building resiliency in the moment by minimizing their own anger and

excusing the behaviour of others, by trying to communicate their discomfort through body

language and tone, and by avoiding situations, such as sex, that create discomfort. As we see in

the next excerpt, many of the women also started to anticipate the process of their body being

public and, in what can be seen as a countermove to the process, covered their bodies. In an

excerpt provided in the beginning of this section, Joan suggests that being able to cover her scar

may have changed her experience of burn injury. Many women who were able to cover their

scarring did indeed tell narratives about the importance of this behavior. In a stark contrast to

being exposed—and potentially viewed as public property and open for commentary—a large

portion of the women interviewed discussed covering their bodies.

Carrie provided an extended narrative about resenting that fact that she was singled out

because of her injury (one of many she included with the same theme). She began by explaining

she, "just really want[ed] to be invisible" and that she hated being "pitied or acknowledged for

being different." The following narrative from Carrie exemplifies the desire to be unseen and to

cover the body.

> P (Carrie): I guess my natural inclination um, to want to hide and to cover myself up
> was…what's the word (4) um, what do you, it's not facilitated it's like when someone -
> it's the psychobabble that's- like you know when you, you're talking someone else up,
> you're it whatever but you know what I mean
> I: Like I want to say enabling?
> P: Yes, thank you, enabling. So my mother very much enabled my desire to cover up so I
> had a (3) large wardrobe of scarves, petal pushers, didn't go I didn't have a swimming
> suit, dresses if possible would have a high neck. So (2) in that respect for going outside,
> the covering up was facilitated in the house it was you know whatever I didn't have any
> kinds of you know I was running around in my underwear or whatever and there was
> never uh any issues there except with my sister who (2) you know, liked to if she was
> being particularly mean you know calling me burned kid and used that to, but you know,
> there's lots of issues there. …Um so there was yeah it was always this desire to cover up.
> And no one challenged that.

Not only did Carrie understand her covering behavior as a "natural inclination" but explained

that it was reinforced by others including her mother, further enforcing the message that her body

should not be shown—should not be public. She appeared to choose her words carefully as

indicated by a long, 4-second pause and asking the interviewer for help in finding the word

"enabling." Carrie also spoke about covering her scars as an adult with makeup, turtlenecks,

scarves, and choosing to never go swimming because she would not wear a bathing suit.

Likewise, Janice explained she started to wear baggy sweats so that she was "covered from head

to toe all the time" and Sabella's photo elicitation interview included several photographs of

clothing and her closet with a narrative focus on how much she changed her wardrobe after her

burn injury in order to have clothing options that covered her scarring.

Aside from clothing and make-up, some women spoke of different and creative ways of

covering their body. For instance Daya, who had three fingers partially amputated as a result of

her injury, discussed holding her body in a certain way as a means of covering her injuries.

> P (Daya): Yea (2) so (2) in fact when I went to ((another country)) and I'd gone to my cousins place to eat, and nobody even noticed anything to ask me what, what happened to your hand, so and I always sit like this so nobody sees the finger ((laughs))
> I: Yeah, so most people don't notice?
> P: No, they don't notice. Even my friends, we are gone out for lunch and they didn't notice so I said, "listen I have to tell you something."

Covering the body could be conceptualized as evidence that woman were dissatisfied with the

way their bodies looked. However, dissatisfaction with appearance was not always evident in the

narratives. Indeed some women spoke about the importance of appearance, particularly in the

context of sexuality. However, not all women spoke about their appearance and, in the narratives

about others' comments, appeared to blame others for creating discomfort, as opposed to

blaming their bodies. A deeper analysis of the narratives included in this study suggests an

alternative conceptualization of the act of covering. That is, covering scars may be understood as

a means of preserving the private body; a countermove to others making the body public. In

these stories, the women were attempting to keep what is private—their bodies—as private,

regardless of their own feelings about their bodies and despite a relational pressure to reveal.

Subsection Summary. In this subsection, *The Body Made Public,* I explored the first of

three struggles of resiliency examined in this study in which many of the women worked to keep

their bodies private following burn injury. This proved to be a challenge as their bodies were

brought into public consciousness in a number of different contexts. The three contexts in which

the women's bodies were made public included:

i.   when other people commented on or questioned them about their injuries,

ii.   during medical appointments,

iii.   and with sexual partners.

All of these situations involved other people and, thus, presented the women with relational tension that they laboured to figure out. It is working through this relational tension that represents a struggle to build resiliency and a move forward in recovery.

More specifically in this subsection, we saw that revealing the body to another, whether it was publically, or in the context of a private sexual encounter, created relational tension for many women following burn injury. The narratives articulated above involved many of the women being singled out, commented on, and exposed, creating a sense that the private body was made public following burn injury. While some women were explicitly aware of their bodies becoming "public property," others explained this process more subtly in narratives about their experiences of feeling exposed. Regardless, the process of the body becoming public created emotional responses from the women including anger, insecurity, and stress. In exploring how these women worked through this tension, emerging as their bodies were exposed, I showed several ways the women engaged to build resiliency. Throughout the section, individual examples of how the women negotiated the relation tension were provided such as by "giving a tone," avoiding others, or by shutting down their own emotional responses. Then, at the conclusion of the section, I discuss a countermove whereby the women covered their bodies in an attempt to protect the privacy of their bodies against the process of becoming public.

If resiliency is understood through exploring what individuals struggle with following adversity, we see here that most women grappled with how to protect their bodies and maintain privacy during a time when other people were prying at the privileged. Thus, the private versus

public tension in the narratives, and the way in which the women work to resolve the tension when in relation with others, is understood as one struggle involved in the process of building resiliency following burn injury.

To Share or to Protect

Up until this point, I have explored ways in which some of the women in this study struggled with relationality in terms of body becoming public. The focus was on the body—or the "disfigured" body—whereby a tension was created when revealing their bodies or when they were exposed by others. In what follows, I explore another way in which some of the women negotiated relationality; however, the focus of this section is on sharing. I delineate two different ways women in this study spoke about sharing.

i. First, they spoke about what I call *shared experience* which refers to the intuitive connection women felt with others who had experienced what they perceived to be an experience similar to their burn injury. This type of sharing was implicit in that it did not involve the exchange of narratives with others.

ii. Second, many women talked about what I refer to as *storytelling* which involves narratives about explicitly sharing stories about their burn injury with another person.

In both cases the women spoke of the importance of sharing in relation to their injury; however, with respect to storytelling, many women were concerned with the impact their stories had on others. They were cautious about burdening or overwhelming others and sought to protect them by means of inhibiting storytelling instead of sharing.

In this section I first explore stories in which many women spoke about sharing (by means of connecting with others who had shared experience or by means of storytelling). I then

draw attention to when, in the midst of their own trauma, many of these women restricted their propensity to share and instead assumed the role of protector. In this role, they attempted to shelter others from feeling difficult emotions related to the burn injury; a task that involved in no small part, silencing or suppressing their own emotional expression. This created a relational tension in which the women struggled to figure out when to engage, connect, and share, and when to hold back and inhibit their stories. Given this tension of opposites, resiliency in this section involves examining how many of the women negotiated sharing their experience of burn injury with others. Thus, to follow, I examine the second relational struggle of resiliency: when to share and when to protect.

To begin this section, I first explore how some of the women understood sharing to be a significant aspect of their recovery through what I call *shared experience.* When these women spoke about shared experience, they spoke about feeling connected with another individual based on having lived through a similar situation. Whether the shared experience was burn injury, or another trauma or illness, connecting with someone who had faced a similar life event was constructed as an important aspect of recovery that created a sense of belonging and mutual understanding. In the narratives about shared experience, many of the women seemed to connect with others without explicitly telling their stories but by simply *knowing* someone else had lived through a similar experience. For example, Carrie, a 48-year-old woman burned as a child, told a story about her father who was in a car accident as a child which resulted in his hospitalization and the loss of his mother and grandfather. Her narrative included a "psychic" connection with her father as a result of both having trauma in childhood which, in her construction, allowed her father to better understand her, as compared to her mother.

Carrie also identified a sense of belonging that came with her frequent hospital stays as a child following her burn injury in which she explained that she felt accepted amongst "lots of people who looked different in different ways." The sense of belonging Carrie felt was not forged through storytelling but rather simply by being around others going through a similar adversity.

> P (Carrie): I was in the hospital it actually- I didn't mind going back to the hospital it actually felt comfortable because I wasn't even if I was in the general surgical ward there were lots of people around who looked different in different ways. And while I would still get you know stared at in the you know if it was in the cafeteria, it was a different it was kind of like I could kind of not worry about things too much, um I felt kind of accepted or.
> I: Kind of like you belonged?
> P: Like I belonged there. Um although, you know, I didn't really like it all that much but there was a lot of um, you know I was I ended up being in wards with other teenagers sometimes and rarely with burn injury people but we had fun. You know we did naughty things with the nurses' station ((laughs)) and you know whatever, it wasn't it wasn't all horrible.

Similarly, Brittany, who was burned as a child, told a story of her brother's childhood illness which she often felt she could relate to based on her familiarity with a childhood burn injury. In her construction, she and her brother faced similar rejection, isolation, and physical hardship which allowed them to share a special connection. This is in contrast to findings from the previous section in which Brittany did not wish to connect with the man at the bus stop who also had a burn injury. What stands out as different between her two stories was the obligation to narrate a story. With her brother, Brittany did not necessarily speak about conversations they had but rather portrayed a sense of mutual understanding based on shared experience. Comparatively, the man at the bus stop was forcing conversation that was focused on her body, requiring Brittany to construct an unfamiliar and uncomfortable joint narrative with a stranger.

Margaret and Joan, in narratives about their involvement in support groups, provided below, specifically attributed strength in their recovery to relating with other individuals who had

shared burn injury experiences. They both referred to seeing others' hardship and resiliency as

being comforting. They seemed to connect to others who also had burn injuries and found

personal strength in others' strength. For example, Margaret, a 56-year-old, spoke about having

her spirits lifted by way of seeing others "rise above" an injury they all had in common.

> P (Margaret): Another thing was the support groups which really surprised me 'cause I thought, "oh well, I'll go and we'll talk" but every time I came out of there I was so umm, I just felt so positive because I saw people who had hardships much greater than mine with such strength of characters ((cries)) Like the human k- human beings are just amazing creatures you know. Some of the things they endure is amazing and they can carry on they just I mean they lifted my spirits every single time I went there you know.

Margaret's tears as she narrated her observations of the support group emphasized how powerful

connecting with others based on shared experience can be following trauma. Margaret's

understanding of the significance of the support group comes from witnessing others' "strength

of character" following burn injury and not necessarily talking about her own experience. Carrie

also constructed a number of narratives about the significance of engaging with others who had

burn injuries and highlighted how it allowed her to move forward in her recovery. First she

explained that, in general, it "made [her] feel much better." She then went on to explain that her

connection with others who had burn injuries helped her identify with the term "survivor" as she

witnessed others speak about being survivors rather than victims, while participating at an

international burn conference. From a narrative perspective, interacting with others with shared

experiences, such as at a burn conference for survivors, may provide opportunities for joint

narration in which others may perform some of the narrative work by providing examples of

what stories look like or what to include when sharing.

Some women suggested that people who had not suffered a burn injury were more

difficult to relate to than those who shared a similar experience, further highlighting the

importance of shared experience. For example, Joan clearly explained, "like it's hard, kind of

hard to talk to people who don't have a burn cause they don't understand." She went on to

explain that she generally only talked about her injury in the context of support groups for

individuals with burn injury, again suggesting that those with burn injuries provide a greater

sense of relatedness. Similarly, in a story about childhood illness, Brittany came to understand

that others "didn't respond automatically how they should" because they had not gone through a

childhood trauma like she and her brother had. Both of these women suggested that those who

have not faced trauma cannot understand it, and thus, found a powerful sense of belonging with

those who shared similar life circumstances. Similarly, in a candid narrative below, Carrie, who

was burned at age 7 years, spoke about her desperation to find understanding through shared

experience. In a story about her "darker moments" as a child, she explained that her younger self

wished that "something horrible" would happen to the "unaffected," or, more specifically, that

her best friend would be burned as well, so that someone would understand her.

> P (Carrie): Yeah and I suppose you know it's and a kind of ironic you know scar tissue is
> thick and yes you inevitably have to develop a thicker skin to get through life generally
> and um, I guess one of the (3) residual effects of that makes me well in some respects it
> should make me more empathetic but certainly as a teenager and even as an adult
> certainly as an adolescent, it was kind of like, really? You're complaining about a zit?
> Like get a life. Um, really feeling like they have no clue and how like a whole part of the
> universe that these people would never know, and my darker moments wishing that
> something horrible would happen to these unaffected people who seem to just sail
> through life
> I: So they could understand or?
> P: Yeah, yeah. And at one point actually consciously wishing that my best little friend
> was burned and it's a horrible thing to think but just because there was I had no contact
> really with anyone else I felt like I was the only one I'm sure you've heard this before.

Here, Carrie understands shared experience as the ultimate way to achieve understanding,

explaining she would go as far as to wish a burn injury upon someone else in order to feel that

sense of belonging.

Connecting with people with burn injuries, or who had faced other types of adversity, created a sense of strength, belonging, and acceptance for many of the women in this study. Engaging in shared experience was part of relationality most of the women appeared comfortable with following their injuries, in part likely as it carved out space in which these women felt accepted and understood. Extending on this from a narrative perspective, engaging with individuals with shared experience may ease the burden of telling one's story in that stories do not necessarily have to be shared in order to connect and, if they are, someone else is doing some of the narrative work. Shared experience appeared to be so powerful in itself, some women were able to forgo verbal storytelling, establishing connection through a mutual understanding of the hardship faced by adversity. However, as I describe in the following, when the women were not able to rely on shared experience to connect with others, some of them relied on storytelling to establish connection, understanding, and a sense of belonging.

Lisa, who was burned in a house fire, constructed a narrative about the importance of storytelling in her recovery. Lisa, whose family history included several house fires, saw storytelling, particularly in therapy, as beneficial because she could talk about the "deepest parts" of herself.

> P (Lisa): But it's like either I write it out in a story or I would have to talk to someone and going to the therapy is really good, and that what I love about that is I don't say anything there, she says, "this is what we're talking about today." And she'll go, "kay, this is what I'm picking up." So it's really, it's an interesting therapy because she gets into it and she pulls the deepest parts of me out which is really good, yeah I, I think talking has always been better for me whatever, like, like we lost a child, talk about it, and what I find is that when I always feel like in a tragedy you're the only one it's ever happened to, I was the only person that ever had a house burn, no I was the seventh in my own family history.

Lisa explained that regardless of the tragedy, she engages in storytelling either through writing or orally, as a way to move forward. Other women, although less elaborate in their narratives as

compared to Lisa, signaled the importance of storytelling as well. When asked directly about

finding strength in recovery, Carrie, Mandy, and Monica all identified talking with others as a

significant component. For instance, Mandy, who had a 20% TBSA burn, recounted spending

significantly more time on the phone after her injury as a way of reaching out to others.

Similarly, Katherine, who was burned on her hand, explained that she used storytelling,

specifically about her burn injury, as a way to connect when meeting new people. She concluded

her narrative strongly endorsing storytelling by saying, "'cause if you don't tell your stories,

what happened in your life, what are you gonna talk about?" Here, Katherine asked a rhetorical

question that suggests telling one's story is essential in communicating to others.

　　　Likewise, on more than one occasion, Monica underscored the importance of sharing

through stories. Firstly, she spoke about the photograph she had taken of her father's car and

remembered going on car rides with her father, who was a priest. In her narrative he would listen

to stories about her burn injury experience. And, within the context of storytelling, she was able

to express emotion as she explained she could, "be real and cry if [she] had to, scream if [she]

had to." Secondly, Monica highlighted the importance of storytelling in the excerpt below by

contrasting it with a time in which sharing her story was restricted.

> P (Monica): No because like I feel like they don't understand and I don't have enough
> time to explain. I mean it's a huge story, I don't really have time to explain it all. But then
> I feel like kind of a little self-conscious after that and I'm like okay yeah, a lot of people
> don't understand but um I know what I understand and how I feel about it and it's true,
> like it's true.

Here, Monica suggested that others would be better able to understand her perspective if they

gave her the time to tell her burn injury story; however, because others did not provide adequate

time, Monica was left feeling misunderstood and "self-conscious." In the above excerpt, Monica

highlighted the connection between storytelling and understanding which suggests that carving

out time to share stories may be an important aspect of negotiating relationality to build

resiliency.

Janice included an interesting perspective on the importance of storytelling in a longer

narrative, not included in its entirety, about the role of her traditional native culture in her healing

process. Using language such as "prayer" and "voice," Janice constructed a narrative about why

saying her thoughts out loud through storytelling, or to use her word, prayer, was important.

> P (Janice): Prayer I think is things that need to be said out loud you know and um they
> don't necessarily need to be heard by anybody else but yourself, cause there just those,
> they're inside you right so if you say them out loud then you can hear them and if it
> sounds ridiculous to you then it's probably ridiculous, you might need to you know
> rethink that right, so that's sort of how prayer works…Your voice is a very powerful
> thing, especially for women. Your voice is powerful, use it, people are listening you
> know.

Although other people were not part of her narrative initially, by the end, she suggested that

"people are listening." Additionally, relationality emerged based on the performative analysis of

the narrative when, in what felt like an attempt to teach the interviewer a lesson, Janice pleaded

with the interviewer to "use it [her voice]." In other words, Janice encouraged the listener to tell

her story. Thus, it would seem, Janice used prayer to carve out space to share her thoughts,

initially with herself, but eventually, with others as well.

In addition to carving out space to share, humor was also identified as an important

aspect of storytelling. Humor was understood as significant because it fostered resiliency and

communicated well-being to others. However, a tension emerged when humor was used to

protect others from hearing stories that would, without humor, be distressing. Therefore, while

humor was identified as a contributing factor in resiliency—something that helped these women

move forwards— it was, on the other hand, also used as a tool to protect others by way of

diluting the distressing aspects of the women's stories.

Katherine explicitly identified her humour as part of her resiliency in a short construction about what allowed her to move on following her injury. She suggested that, "[m]aybe the fact that [she] was, um, more joking about it rather than self-conscious about it" made her better equipped to cope with the trauma of burn injury. Mandy also identified humour as an important aspect of resiliency in an excerpt below that highlighted the interpersonal nature of humour. She began her narrative with a joke about how her injury made her more unique and then continued by explaining that, together, her family used humour to "get through things."

> P (Mandy): I'm a little more unique than I used to be, like it's, you know, eh, I mean I made jo-, we make jokes and that's how we get through things in our family, you know. Won't even have to take DNA to identify the body because I'll be ((laughs)). Like it was, so we did deal with a lot of it with humour right from the start, like they told me at Halloween I could go out as a joker or a mummy or, and we di-, we kind of dealt with it that way, so, but as time went on I think I am, like I do find I can get um (5) um pretty morose for no reason. I just got tired of it, like I, I was okay, I felt my job was to reassure them, yeah they could see the burns if they wanted, but I'm fine and, and now I'm just kind of um use a lot of humour to deal with most of it.

Above, Mandy explained that she used humour in her stories when she no longer felt able to reassure her family. She, thus, understood her role in her family was to control others' emotional experience or to make certain others were not overburdened. It is not clear whether Mandy believed herself that she was "okay" and she did acknowledge that she was "pretty morose" but, regardless, had to "reassure" her family that she was "fine." When Mandy got tired, humour seemed to be used as a last resort in communicating well-being to others, even when she may not have been doing well.

The idea of portraying well-being when, perhaps, one is in distress was introduced in Mandy's narrative constructed about humour above. Lisa, who was burned on her face, arms, and legs, also commented on her use of humour in recovery. She further expanded on this idea when she aptly pointed out that humorous stories and jokes can also be used as avoidance by

explaining, "you have to make sure that humour doesn't cover or mask other emotions—that you're allowed all ranges." Indeed, many women explained that, at times, they intentionally covered—or silenced—their own stories. Instead of opening up to others and sharing to find strength as we saw above, I show in what follows how many of the women also spoke about protecting others by not talking or expressing themselves. Similar to the countermove explored earlier when some women covered their bodies as the private was made public, here the countermove to sharing is silencing their stories. However, this countermove was not in self-protection, as it may have been with respect to the body, but rather a move to protect others. In both cases, a tension emerged—private versus public and sharing versus silencing—which involved negotiating relationality, and by extension, a struggle of resiliency.

The countermove, a move away from sharing and towards protecting, emerged in narratives in which the women spoke about how others were impacted by their injuries. Here, in the narratives, these women would acknowledge others' negative emotions relating to their burn injuries and then discuss how they would try to diminish these emotions by not talking about their injuries. For example, Daya, whose injury was a consequence of a medical event in her home which resulted in loss of consciousness at a time when her adult son was home, included a photograph of her adult son as part of her photo elicitation interview. To explain the photo, Daya constructed a story, found below, in which her son blamed himself for her injury. In this excerpt, Daya promises to not express her emotion or speak of her burn injury, in hopes that her son will not continue to blame himself or think "I should have been there earlier."

> P (Daya): After my son started blaming himself yeah. So I'm never going to show him that I was sad, I'm angry and, and depressed, or anything like that, so that he would feel every time that, "oh I should have been there earlier, I should have." Because he has his life, maybe longer than mine, and I don't want him to live in that stages. So, that's when I change. That I'm going to be happy. Then nothing matters, no.
> I: Your son felt like that?

P: Yeah, and then I didn't want him to be depressed at all and I sa-, really started listen, "we are not going to talk anything what happened in the past, now we are going to look only in the future, I am still here, and my hand is still, even though injured, it will be alright, so you should never feel it like that." And I never even thought,(1) and then I decided I'm going to be happy, so that he can, all his life will not be with the guilt yeah.
I: Um hmm, you feel like, if it really was hard for you he might feel your (1) pain.
P: Yea he, like if I showed any pain, if I kept say, "oh I'm feel so sorry" or something, then he would go back to the guilt and, "I should have been down there" or something, so, I never, and I decided, I'm not going to. But it took me awhile to feel that, even though I told him we are not going.

In Daya's narrative, the theme of protecting others emerged. Because Daya believed her son blamed himself for the accident which caused her injury, she vowed to not speak about her reaction to the injury. She suggested at the beginning of the narrative that she did feel sadness, anger, and depression, but suppressed this with a happy performance; however, it is far from clear whether she *was* happy. She shared that she did not allow herself to show "any pain" because she wanted to protect her son from further feelings of guilt associated with the accident. Daya constructed a narrative in which she inhibited her own experience in a way she believed would prevent her loved one from a distressing emotion such as guilt. Even while dealing with her own trauma, Daya protected others and took responsibility for their emotional experience, as we also saw above when Mandy used humour to reassure her family.

Carrie, who sustained her injury as a child, spoke of the impact of her injury on others throughout her interviews. Her overall story entailed her entire immediate family struggling as a result of her injury and them taking responsibility for her injury. She acknowledged that, "[she] knows it affected [her] parents" and suggests that some of the "hardship" her sister faced throughout her life was related to the injury. She went on to suggest that it would have been understandable if her mother had a "nervous breakdown," and suggested that this likely happened. In response to her family's distress, as we see below, Carrie restricted the sharing of her story and attempted to protect others by not talking to them about her burn injury. In a larger

narrative about being dissatisfied with a medical professional, Carrie describes how she

understood the importance of talking with others.

> I: I ended up calling calling his office and asking him for a referral
> I: To another plastic surgeon?
> P (Carrie): No, no, no, to a psychiatrist or psychologist uh because I needed to talk to
> somebody. I was, I felt like I was going nuts. And um, and I couldn't - I never talked to
> my parents about things. We talk about the accident if it came up, it was in you know,
> very um...we didn't sit down and talk about stuff like that. 'Cause I was protecting them;
> I didn't want them to feel, I mean they felt responsible even though they were not
> responsible.

Carrie highlighted the tension between restricting and sharing when negotiating relationality with

her family. She began by explaining she "needed to talk to somebody," thus indicating she was

aware that sharing her stories was necessary. However, she went on to explain that she was

"stoic" and would not talk with her family because they felt responsible and she wanted to

"protect" them from feeling "guilty and upset". This propensity to protect others appears to be

far-reaching across the lifespan. Above, Carrie discusses doing so as a child while examples

from mothers, grandmothers, adult daughters, and wives are also present in these findings. Thus,

in a variety of different relational dyads women move to protect others from difficult emotions,

primarily by not talking—by not sharing.

Below, Margaret, who had primarily facial burns, told a story about her mother's

emotional reaction to the injury. Margaret shared that dealing with her mother's pain was

difficult and that she attempted to protect her from further distress by not allowing her to visit for

approximately a year following the injury. Although Margaret acknowledged she was self-

protecting from her mother's pain she also indicated that she believed her mother was incapable

of witnessing the injury, and in this sense, Margaret was protecting her mother as well.

> P (Margaret): My mother took it particularly hard; she lives in ((another city)). And, that
> was probably the most difficult emotionally, to deal with her uh pain because she's, she's
> uh (4) uh, she's a very umm, she gets umm, worked up over just the simplest minor

things. And apparently she was actually hard on uh the family, like my my brother and sisters, because she was so overwrought. And, you know, she couldn't- actually, that was the hardest thing, she was, she was just beside herself when it happened. And I know she was uh (2) she was being difficult with uh my brother and sisters, and I know she wanted to come out but I also know she would have caused absolute chaos. And I know that my husband and my children were grieving and it was very stressful for them. I also had a son living in ((another city)) who drove all the way to see me in the hospital; took time off of work. And uh, I know that she would have caused problems 'cause that's just how it's been throughout- that's the family dynamic with her. And uh, the hardest thing to do was to tell her not to come, that was very difficult.

Above, Margaret prevented her mother from visiting in hospital to protect her from distress; a move that Margaret described as "very difficult." Thus, while working to recover from a trauma, Margaret was also struggling to regulate family dynamics and other people's emotional experiences. Likewise, Mandy wondered how seeing her injury would affect her adolescent granddaughter and explained that in order to protect her granddaughter from any potential impact, Mandy, who had burns on her arms, legs, back and face, prevented her granddaughter from visiting in the initial recovery stage. In contrast to the narratives at the beginning of this section where others were approached to provide strength and healing, here others were kept away. Furthermore, we again see women taking responsibility for the relational dynamics and emotions in a pattern in which they restrict, deny, or silence their own experience to protect others. In a move to protect, many of the women put their own needs, for instance sharing their burn injury stories to achieve connection, second to that of their loved ones. Below, Mandy aptly summarizes the role she, and others in the study, took on with some satisfaction that they were protectors.

P (Mandy): My son calls me uh low maintenance. Well that's that role. Where you kind of put all your needs on the back and then look after everybody else.

Subsection Summary. We see in this section that many women seemed to struggle to figure out how and when to share their stories with others. These women were certainly open to

connecting with others who had experienced similar medical events. However, beyond sharing

with those individuals or in contexts of obvious support, it became less clear how exactly the

women decided if and when, or with whom, their stories were too much. The pattern of

inhibiting storytelling seemed to be more prominent in familial relationships with women sharing

stories about protecting grandchildren, adult children, partners, mothers, fathers, and sisters

whereas openness to sharing seemed to emerged particularly outside the family unit.

Interestingly this pattern of protecting spanned various types of familial relationship and

emerged across the lifespan with one participant recounting a story of protecting her family when

she was still a child and others providing such examples as grandmothers. Overall, in

relationships with others, most of the women were compelled to connect through shared

experience or storytelling as a source of strength and understanding. In order to do so, however,

these women had to carve out the space in relation to others in order to share. Moreover, most

were, at times, uncertain about sharing with others because they did not want to burden or upset

others with their stories. As a result, many of the women acted as protectors by not talking, not

expressing emotion, or not being present—that is by *not* sharing in experience or in storytelling.

As protectors, the women avoided or minimized aspects of their own stories in order to control

and reduce others' distress.

It is not clear, however, that the women's attempts to protect others did indeed help

others following burn injury, although there seemed to be some pride in being strong enough to

do so. What was clear was that if the story or experience of burn injury was deemed by the

woman to be too much for someone, she would negotiate the situation by silencing her story,

avoiding contact, or using humor. Struggling with relationality with respect to when to share, and

when to silence and protect, thus becomes one way women struggled to negotiate what worked for them, and in doing so, became more resilient.

Accepting Support from Others

Support from others is undoubtedly an important part of recovery from burn injury. It is not surprising then, that many women constructed narratives about the importance of support they received from a wide range of individuals including family, friends, and health care professionals. However, despite the commendation for support from health care professional, family members, and friends alike, most women struggled with associated feelings of guilt about needing others and appeared to lament the loss of independence and their role as care-taker. In the previous section I looked at relationality in terms of sharing one's experience with another person. In this final section, I focus on relationality in terms of receiving direct emotional or instrumental support from others. The process by which these women worked through what it meant to be supported represents the third relational struggle in building resiliency following burn injuries. In what follows, I first explore instances in which most of the women were open to support and appeared comfortable relying on others. I then move to further explore the tension that arises as they grappled with a sense of dependence and feelings of guilt in another attempt to build resiliency. The findings in the current subsection represent a distinct timeframe in that the women were only dependent on others while they were recovering physically from the injury. In a sense, this phase is transient and was in the past for many of the women at the time of the interviews. In comparison, the loss of privacy and sharing of one's story, discussed previously in the findings, represent more permanent phases which may last forever.

One major type of support women received following burn injury was from health care providers including a wide range of professionals such as doctors, nurses, home care workers,

occupational therapists, and psychotherapists as well as more unconventional healers such as a

reiki specialist and a body talk therapist. In majority of the narratives, the women presented

themselves as open to receiving support from health care professionals and praised the care they

received. Below, Mandy's story in which she lavishly praises home care workers, reiterates the

sentiment expressed in many of the women's narratives about the role of health care

professionals.

> P (Mandy): Bless homecare, I love homecare. So it's pretty obvious I had a super support system in my family, but homecare was right up there. They were like huge part of it all.
> I: What was it they were doing that was so helpful or
> P: Um explaining, reassuring, um there was two ladies that were the basic, there was one she was just, she was fa-, well you get attached cause they, they wi-, they came every day and the, they would phone before I come cause I wouldn't take my pain killers.

Like Mandy, the women generally constructed narratives in which they emphasized how helpful

and encouraging health care providers were. Some stories included health care providers

exceeding the women's expectations of care. In the excerpt from Mandy above, she reported that

home care workers "came every day" and would call her to remind her to take her pills. She also

explained that her home care workers addressed her emotional needs, encouraged her to

becoming more active, and explained potential reactions to trauma. Moreover, Trish described

how her home care workers became her social outlet when she was housebound as a result of her

injury, explaining she would often make them coffee so that they would spend time and talk with

her.

Some women ascribed emotional meaning to the health services being offered and even

appeared to form attachments or close relationships with their health care providers. From a

structural analysis perspective, this is exemplified in Mandy's use of the word "love" in her

narrative and by suggesting an "attachment" was formed. Similarly, Margaret spoke about

"wanting to please her" in reference to a "very supportive" occupational therapist. Margaret also

spoke about an influential relationship with health care provider and performed her gratitude by

crying while telling a story about a volunteer, whom she refers to as "an angel," who would often

come to her hospital room to perform reiki during recovery. Prior to where this excerpt begins,

Margaret discussed how reiki, an energy-based form of healing, relieved her physical pain as

well as the psychological impact of constant and intense pain.

> P: (Margaret) And I remember one time she was there, and she put her hands on my face
> she touched my face; you know I had this scabby, oozy face. And when she did that, it
> just made me, I can't remember, I don't think I cried but I cried in- inside. I thought, oh
> my god ((cries)) a stranger doing something like that, you know, to this (2) mucked up
> face. I just. She's just an angel.
> I: She would touch your face? [P: Yep] Was-
> P: The fact that she touched my face I couldn't believe it. Cause you know, you think,
> you know I felt like Quasimodo you know. And it was like, just a, it was just a, pure,
> umm. Just uh, I don't know how to describe it. I mean, you know. Instead of being
> repelled she, she just, she she was a healer and it was uh. Oh wow. It was emotionally
> powerful, you know?

In addition to pain relief, this interaction was also significant based on the meaning assigned to

touch. Here, touch was constructed by Margaret as "emotionally powerful" and seen as "pure"

and healing. We see just how emotional touch is to Margaret when she said, "I cried on the

inside." The emotion of this experience was further emphasized by the transcription indicator

and field notes which both indicate she was crying while narrating this segment. She portrayed

being shocked that a "stranger" would touch her "scabby, oozy face" and a sense of being taken

care of emerged. Here, Margaret did not try to avoid contact with professionals as she did with

other individuals in her life, discussed at various times during her interviews, but rather freely

allowed another person to touch her injury. We see in all of these narratives about support that

the women constructed close and caring relationships with those who provided professional

support and appeared comfortable opening up to and relying on health care providers. Even

when providers were viewed as going beyond what was required, these women happily engaged

in receiving support. In fact, the women appeared to give more credit to professionals for their

healing than they gave themselves. Despite the recognition of great effort on the part of the care

providers, these women did not include themes of guilt in their stories about support from

professionals, which will be contrasted in comparison to family relationships later on.

The physicality of burn injury not only required the attention of health care providers,

identified above, but also often left these women limited in their day-to-day functioning

particularly with respect to household responsibilities. Many women in this study also spoke

about instances of welcoming support from others aside from health care providers such as

family and friends when the physical limitations of the burn injury hindered their day-to-day

functioning. An excerpt from Trish's interview (a mother of two young children) exemplified

how support was constructed in many of the narratives.

> P (Trish): These are kinda like my family. This is *Patricia ((sister-in-law)) and her kids.
> And I took just three of them ((pictures)). Um, they were the ones that took care of
> *Kaylen ((her son)). So I couldn't, I could barely walk, because of where the burn was. I
> couldn't (2) it was so painful, like I was on morphine, I couldn't take care of my own
> child. So because she was amazing she came every single day, she picked him up,
> dropped him off at the end of the day. I could, I don't know what I would have done
> without her because my mom like actually doesn't live close by. She lived in Quebec at
> the time so I had no support except for her. Oh my god. So that's why I just took pictures
> of them. My family is just like everything now.
> I: And so that was during your recovery that you needed
> P: I needed her, bad. I don't know what -I couldn't have. I don't know what I would have
> done with him. Being a new mother too at the time, it was nuts.

This excerpt, like others from many of the women, included Trish's open acknowledgment of her

need for others when she spoke about her sister-in-law Patricia and said, "I don't know what I

would have done without her" and "I needed her bad." Additionally, Trish's role as a mother,

which she described as "nuts," was highlighted in her narrative as she depicted what it was like

to try to care for a child while recovering from a burn injury. Because of her physical limitations,

Trish could no longer fulfill this role and had to rely on her sister-in-law to take over her care-

taking responsibilities. Although Trish's story was about her limitations in childcare, other women told similar stories about their changed care-taking roles with respect to difficulties completing tasks such as cooking, cleaning, yard-work, and other household chores which are explored again below.

Emotional support, defined to include the provision of empathy, love, and trust (Langford et al., 1996), was also included in many narratives. Once again, most women were typically open to receiving support from close others—this time with respect to emotional support. In what follows, one woman discusses the importance of the emotional support she received from her friends. We see in her excerpt a contrast compared to *The Body Made Public* subsection in which the women's bodies were made to feel exposed when others focused or commented on the body; however, below, others "look past" the body (scars). These contrasting experiences emphasize the role others play in negotiating resiliency. In *The Body Made Public* subsection, others forced the body into the public, requiring the women to figure out how to maintain their private bodies, while in the story below, others provided comfort and support by loving the imperfect person without dwelling on what made the body different. In the excerpt below, Janice who had burns on her chest, explained that her friends demonstrated support by looking past her scars and allowing her to "just be [her]."

> P (Janice): They ((her friends)) look, they, they don't, I don't know they just (2) make me, because of the way they look past all of my scars and everything they don't, you know it's just, that's just me you know and, and it allows me to just be me, (1) you know, they don't a-,you know whatever, they don't ask for s-, every now and then they'll ask, okay "well what's that all about," right.

She continued to explain that this allowed her to feel comfortable with herself and "brought her a long way," implying their acceptance of her facilitated her recovery process. Later in her interview, Janice reiterated the importance of emotional support from others by sharing a quote

from her niece who said, "love is losing your teeth and still being able to smile really big because you know your friends and your family love you, no matter if there's pieces of you missing." In the broader context of her interviews, Janice spoke about body image a number of times, including in reference to her daughter's struggle with bulimia and ultimate suicide. This not only suggests she may be acutely aware of the importance of the body's appearance but also suggests that she feels supported most when others do not dwell on one's outward appearance. This further emphasizes the earlier assertion that these women may have been trying to move away from or fight against others focusing or commenting on their bodies.

Thus far, narrative extracts in which women constructed others as supportive, helpful, and facilitative in recovery have been presented. What is not obvious in these extracts, but emerges from a structural analysis, is that the language used implied complete incapacitation and reliance on others. For instance, many women used absolute language such as "anything," "everything," and "twenty-four/seven" in their construction of narratives about instrumental support, suggesting a high level of dependency following burn injury. Mandy described the support she received as "babysitting," evoking a helpless, child-like need for care-taking. Many, like Trish above, suggested they did not know what they would do without the help they received and suggested they would not be able to function or recover without it; thus, placing high importance on others in the recovery process. In this sense, as they did with the health professionals, many women seemed to give family members and friends more credit for their healing than they gave themselves.

It is here where the resiliency struggle emerges as I begin to explore the intersection between support and dependence. A tension developed between wanting support from other people while, at the same time, wanting to maintain or regain independence. What independence

meant to these women varied but the stories included examples such as making medical

decisions, performing household duties without help, and taking care of themselves (i.e. being

able to cook and get dressed) and others. Overall, negotiating independence involved a push and

pull between when, how, for what, and from whom the women would accept help. Although

support was often constructed as instrumental in recovery, as we have seen thus far, in the

narratives to follow, I uncover a tension in accepting the support because it created a sense of

dependence they did not like and, in some instances, associated feelings of guilt. Because these

narratives were about support from others, they were all about relationality to varying degrees.

What I emphasize, however, is that the ambivalence between accepting support and

independence is a struggle played out in relationships with important others. It is in what

follows, that we begin to see the women work through the tensions between support and

dependency to build resiliency.

In the excerpt below, the conflict between support and dependency was dramatically

highlighted. Katherine, the youngest women to participate in this study at the age of twenty,

began her narrative by acknowledging how nice it was that her sister took on a care-taking role

(a role she reported was typically hers) but then concluded her narrative by expressing

abhorrence towards her dependency, which she later explained felt like being a child again.

> P (Katherine): Oh it got better. Well it was kind of nice at times 'cause my sister she
> does, didn't do a lot around the house and then like she's pretty caring person so when
> you, when everyone's just fine she's just all attitude blah, blah, blah, but when you, her
> sibling is hurt she's there for you and she's, so she was just like do you want some soup,
> do you want to make you some soup, do you want some this, do you want that and she's
> like, I'm like sitting in bed I'm like kay, and she's like, she's coming back and forth and
> doing all these things, I was like kay, I can get up and get my own bowl. And she's like,
> "no, no it's okay." I was like, I burnt my hand, not my entire legs, I can walk. She said,
> "no, no, no." I'm like ahhh ((laughs)) so maybe ve-, it was like nice of her, it made me
> feel good that she's doing something and that she cared, but I hated the fact that I was
> like being a dependent.

Other women also mentioned loss of independence in narratives constructed about relying on others to perform tasks that had previously been part of their role. Daya spoke about a loss of independence in the context of not being able to care for herself or her family following her injury. She told a story about being able to again make a fist with her injured hand and that it made her feel independent again, implying a loss of independence due to the limited functioning in her hand. Daya's narrative about regaining independence was about not previously being able to perform regular household duties which contrasts with the narratives discussed above in which many of the women (including Daya herself) praised others for stepping in to perform the tasks the women could no longer complete. Thus, it is hard to decipher whether allowing others to step in and complete role-specific tasks was welcomed or considered to be a crossing of a boundary that created a loss of independence. The difficulty teasing this apart is likely a result of the women struggling with the same tension as they were likely ambivalent.

More generally, Mandy explained, "I'm pretty independent and I really kind of felt I was losing a lot of that and it was a struggle to get it back." Structurally, Mandy's use of the word "struggle" in this short quote highlights that there was a process in which she had to fight to regain independence. Brittany also addressed the issue of independence in a narrative in which she vacillated between encouraging others with burn injuries to ask for emotional support and suggesting that they find a way to "deal with it on [their] own." It was as if Brittany was grappling with her understanding of support throughout her own recovery, wavering between allowing others to be supportive and dealing with her injury on her own. She seemed to work through the conflict by the end of her narrative when she said,

> P (Brittany): It's a combination of that you feel independent because you're doing the work for it by yourself, it's not being pushed on you, combined with having other people who help you with it.

After negotiating whether one should let others know what they need and ask for help, Brittany resolved the tension between independence and dependence in her narrative by reaching a middle ground and recognizing that they may not be mutually exclusive concepts.

Like Brittany, Olivia, a forty-one year old woman, also spoke about trying to find a balance between independence and dependence following her injury. While explaining why she believed she had not experienced adverse psychological outcomes following her burn injury, Olivia suggested it was because she was independent; however, as she continued, she suggested that sometimes she should let her husband do things for her. We see the ambivalence between her self-concept as an independent woman while also considering she may require help.

> P (Olivia): Um I think I was, well I was brought up to just a go getter, um I think it's-sawy, the way you're brought up, um I'm always independent, um. I have no problems doing things my own way you know doing things to get things done, um I don't need somebody to take care of me and just somebody guide me, teach me and I'm good and I can do it, yea
> I: S-, would do you call that resiliency? (3) like do you feel resilient?
> P: Yes that could be a bad thing though ((laughs)). Um I think it is resilient, um (3) I think it's more positive yes it's, it's, it's a, I think it's a positive thing, um to be a go getter, um and not needing somebody to do things for you, um (4) my husband tells me there's lots of times like kay let me do it and you know I don't have to do everything. Um but that's where, cause I need to, I need, I, I need to, I'm willing to teach me and I'm willing to and there's times where he's like, "kay, can I do this."

Here, Olivia exerted her independence when she said, "I don't need somebody to take care of me," in a sense pushing back against support. However, she drastically vacillated in her understanding of independence as she explained that she thought it was a "positive thing" to "not [need] somebody to do things for you" but then, also suggested "that [not needing somebody] could be a bad thing though." It appeared Olivia generally considered herself to be independent, even in relationships, but was reconsidering, in a discussion about resiliency, that perhaps she could learn from and "need" others at times as well, something her experience forced her to consider. Mandy also pushed back against support in her relationships, turning down help

offered by others. In the excerpt below, in which she was talking about not relying on others to

take on some of her responsibilities, such as cleaning her eavestroughs, she reflected on her

recovery and wondered if she moved too quickly.

> P (Mandy): I know in their eyes I was doing too much and I was trying to progress faster
> than I probably should have, but it, it, it seemed to be the best way to get through it to me,
> like get on with business, like it, there's things you're not capable of, you try them, if
> you're not capable, you just don't do them because it what, I mean when you don't have
> hands (3) to cooperate with you it was, and then as I started to get better I found more
> things that I can do.

Along with struggling with dependency, some women also grappled with feelings of guilt

associated with relying on others in the context of support. Although Trish, who was burned

when her first child was an infant, expressed gratitude for her family in a narrative extract

explored earlier in this section, below, she expressed guilt associated with not being able to

fulfill her role as a mother. She explained that she left "useless" as others had to step in to take

over childcare.

> P (Trish): I cried a lot because like I should be there for my child and I just basically like
> lied on the couch watching T.V. all day and I'm like, I felt there- there was nothing I
> could do. I couldn't even hold him.
> I: So you felt bad that you weren't able to kind of be there taking care of him
> P: Well a lot of guilt, ya. I just felt useless, like trying to make supper, do anything like
> and you're just crying to like moving, sitting down hurt.

Trish explained that not being able to do what she "should" do resulted in many tears ("I cried a

lot") and "a lot of guilt." In her role as a mother, Trish struggled with what she was able to do

("lie on the couch") and what she should do ("take care of my child"). She appeared pained that

she was not able to provide for and nurture her son, again using absolute language when she said,

"there was nothing I could do. I couldn't even hold him." Her role as a mother was greatly

altered, creating sadness and guilt. Daya, a seventy-two year old woman, who repeatedly

identified as a wife and mother, explained her reliance on her husband to complete activities of

daily living also resulted in feelings of guilt when she suggests below that "it put a lot of pressure

on him."

> I: But you weren't able to do what you typically or normally did around the house and, and your, your family kind of picked up?
> P (Daya): Yeah, husband, well mainly my husband. He would do cooking, no sh-, grocery shopping because my son doesn't drive so he's, he has a mental problem. So, eh (2) grocery shopping, then in the winter, it was winter it happened in January, so what it, like shoveling and things like that. He has to work also, not for [son's name] because he [has intellectual limitations], but they call him [her husband] off to some meetings and things like that so he was to work that taking me to the doctors, to the appointments and things like that so it, eh, lot of pressure was on him.

Interestingly, considering the narrative above, Daya also spoke about how her family supported

her and emphasized that it was important they did not criticize her or blame her for the accident

that caused her injury. That is, Daya felt supported by her family when they absolved her guilt by

"not telling me that I'm guilty."

Lisa, a mother to adult children, also included the construction of guilt in her

understanding of support. Below, she reflected on some insight she gained in therapy about being

able to accept help from others.

> I: So would you say the fire helped that shift happen in terms of putting you on the list of priorities?
> P (Lisa): Yes, absolutely, but still like it's like, I mean I still feel guilty if I don't take care of everything but it's like okay you know what, like I'm going, I'm going back to um like I ha-, like and this is what body talk taught me. I had to learn to deserve good things, and, and she's like that's the, she says you don't believe it at all and you are killing yourself atom by atom because you don't believe you deserve good things, so she's been working on that, and I walk around "I deserve a life of joy, and ease and glory," and I say this all the time and she's like get it into every, every atom of your being.

Here, although Lisa recognized she needed to be taken care of in addition to taking care of

everyone else, she expressed guilt around not being able to do "everything." Lisa's accepted role

as caretaker resulted in feelings of failure and self-blame when perfection in care-taking was not

attainable. With insight into her own behavior, Lisa constructed her drive to take care of

everything except herself as a function of not feeling worthy. A tension between taking care of

the self and taking care of the other emerged in the narrative excerpt above which adds to our

understanding of how many women worked through complicated relational tensions associated

with accepting support. In fact, most examples in which the women spoke about guilt involved

stories about not being able to fulfill their roles as caregivers.

　　　　Subsection Summary. Most women constructed ambivalent narratives about support

following burn injury. On one hand, most women viewed themselves as in need of help and were

pleased to receive care and support from others. However, accepting support from others during

recovery also represented a loss of independence, a quality many of the women expressed having

taken pride in prior to their injuries. Accepting, and even needing support, at times, created

feelings of guilt that revolved around many of the women's understanding of their role as care-

giver, not care-receiver. Considering this phase of recovery was in the past at the time of the

interviews for most women, it is surprising that the loss of independence emerged as such a

strong theme. It was as though, even with regained independence and care-taking abilities, the

women continued to experience guilt for having, at one time, failed to maintain their roles.

　　　　It is not clear from the interviews what exactly impacted the women's decisions to accept

or reject help, however, one possible explanation is that help may have been more easily

accepted from health care providers, or people who are "supposed to" help as opposed to

accepting help from friends or family members, which may create a sense of burden. The women

appeared to express more guilt about accepting support from individuals to whom they would

normatively provide care. This mirrors the pattern emerging with respect to sharing their stories

in that the women appeared more eager to protect, and therefore not share with, those close to

them. Similarly, accepting help in areas in which the women felt unable to help themselves, for

example medical care, may have been easier as compared to accepting help in areas in which they were used to excelling, for example, taking care of others.

Figuring out how to accept help in a time when support is highly valued (as we saw at the beginning of this section) was shown to be a complicated process in which many women had to fight to regain independence while also accepting help when needed in order to build resiliency. That is, resiliency was not achieved by sweepingly accepting support or by rigidly maintaining independence but by negotiating and finding balance between these two important aspects of recovery. Just as Brittany resolved the ambivalence in her narrative by realizing support was not a black and white experience, others may need to grapple with their own understanding of support in order to move forward in their recovery.

Chapter 5: Discussion

Summary of Findings

The goal of this study was to contribute to a better understanding of the resiliency process for women following burn injury. As explained in the introduction, resiliency for the purpose of this thesis was defined as struggling through tensions of opposites in adversity. Therefore, I focused on exploring tensions or areas in which the women struggled in and through their narratives. The narratives were not clearly about resiliency, or "bouncing back", as the women included narratives about times when they did not struggle or when they appeared to be adjusting "poorly". These disparate narratives were included throughout and created the ambivalence that is the focus of this thesis. Comparing narratives both within and between participants, three main areas of ambivalence emerged all arising in contexts involving relationality with others. The women told stories that included a tension between feeling two seemingly contradictory ways about relationality. In other words, they told stories about how other people helped them, comforted them, listened to them, accepted them, shared in experience with them, and understood them while at the same time, telling stories about relating with other people that resulted in feeling uncomfortable, exposed, misunderstood, vulnerable, dependent, and guilty. I suggest that in coming together and connecting with others in this tension, women find themselves in a position to negotiate resiliency. In the findings section I explored three overarching relational tensions that emerged in the women's narratives including *The Body Made Public, To Share or to Protect* and *Accepting Support from Others*. In what follows, I discuss three ways in which the women negotiated each of these relational tensions, and by extension, resiliency. The women negotiate these tensions by:

i.   fighting against the process in which their bodies were made to feel exposed (*The Body Made Public* section),

ii.   deciding how and when to share their burn injury experience with others (*To Share or to Protect* section),

iii.   and figuring out how to accept support while struggling to regain independence (*Accepting Support from Others* sections).

It is this, working through, figuring out, and moving on which I suggest represents the process of resiliency development.

Although there are many ways to think about gendered behaviour, I propose that many women in this study engaged in relational patterns consistent with Jack's (1991) theory of self-silencing in order to work through each one of these relational struggles of resiliency. Discussing the findings using this theory emerged from the analysis of the data and was not the proposed or intended framework from the outset of this research. I will begin the discussion by contextualizing the study findings within the framework of Jack's self-silencing theory, which I review to follow, while also including other relevant literature. I will then conclude this thesis with a discussion of the limitations, strengths, and implications of the study, and offer recommendations for future directions.

Self-Silencing Theory

Considering the focus the women placed on other people in their stories after burn injury, I will use a relational theory about how women behave in relationships in order to understand the findings. In each of the three subsections of the findings, the way in which the women described their reactions and behaviour in relational situations can be understood using one of the dimensions of Jack's (1991) relational self-silencing theory. Self-silencing is a cognitive schema

prescribed culturally, which guides women's social behaviour by inhibiting the expression of

emotions in order to maintain close relationships. The theory includes four dimensions including

silencing-the-self, *the divided self*, *care as self-sacrifice, and externalized self-perception.* This

theory is based on the assumption that women primarily organize their personhood or sense of

self around affiliating with others and maintaining relationships, which has been supported by

other authors (e.g., Fehr, 1999; Miller, 1976; Radden, 1996). Jack argues that women, from a

young age, are socialized to be empathic nurturers, placing emphasis on maintaining connected

relationships; thus making self-silencing more common for women because certain patterns of

interaction encourage the development of certain traits in females, different from males, such as

proximity, nurturance, and responsibility. This theory describes a sort of idealized femininity and

suggests that women ought to be emotional nurturers, even if this requires some denial of the

self. By adhering to these cultural expectations, women may feel pressure to silence parts of

themselves in order to maintain important relationships.

In the women's narratives, we saw that many women silenced, shut down, and ignored

their own experience when in a tense relational dynamic. Narratives about silencing storytelling,

rejecting support, covering the body, and avoiding relationships all fit into Jack's (1991) self-

silencing theory. While Jack's original theory is comprised of four dimensions, I explore three of

them, *silencing-the-self*, *the divided self*, and *care as self-sacrifice* in order to understand the

study findings. I applied these three dimensions because they are most relevant to the study

findings and I was able to map each dimension onto one of three struggles of resiliency explored.

For example, I argue that the way in which the women countered their bodies being made public

is consistent with, and builds on to, the silencing-the-self dimension of Jack's theory. The

externalized self-perception dimension, which entails judging oneself by others' standards (Jack,

1991), was not applied to the findings because this dimension did not fit as closely with the data

with respect to negotiating interpersonal tensions.

In applying dimensions of self-silencing to the findings, I suggest that women use self-

silencing to ease tension they feel in relationships in the midst of trauma in order to maintain

continuity and in doing so, to build resiliency. It is important to note, as I will explore later in

this section, that self-silencing has been shown to have negative consequences for those who

engage in this relational pattern (e.g., Ali et al., 2000; Faber & Burns, 1996; Jack, 1999).

However, in coming to terms trauma, it is reassuring to maintain role stability and self-continuity

(Medved, 2010), and thus, challenging their socialized behaviour, that is the broader political

framework, at that time may not be warranted. I argue that the women in this study framed self-

silencing behaviour in a way the allowed them to create a world in which they could live and

move forward following adversity.

Silencing-the-self. One specific dimension of self-silencing called "silencing the self" is

the extent to which women censor or inhibit the expression of their thoughts and feelings to

avoid conflict in relationship (Jack, 1991; Jack & Ali, 2010). There were several narrative

threads in *The Body Made Public section* which included women inhibiting their own inner

experience in the midst of relational tension. For example, many women were angered when

their putatively assumed private bodies were made to feel like public property yet did not tell

stories about being angry with others. Rather, the women told stories about ways in which they

were able to defuse their anger or avoid the maddening experience by hiding themselves in what

I liken to silencing-the-self. The women silenced their emotions not only by keeping quiet about

their anger when their body was made public but also by denying parts of themselves by

avoiding relational situations and covering their bodies to ensure others would not trigger the body made public process.

Not surprisingly, bodily appearance is a significant area of interest in the burn literature. Studies investigating the impact of burn injury with men and women together have identified a preoccupation with scar appearance and management, struggling with the definition of physical beauty, and high levels of body image dissatisfaction (Badger, Royse, & Moore, 2011; Mirivel & Thombre, 2010). There is an overwhelming assumption in this literature that the appearance of the body after a burn injury creates distress for the individual and is the cause of social difficulties such as bullying or staring (Bergamasco, Rossi, Amancio, de Carvalho, 2002; Fauerbach et al., 2002; Lawrence, et al., 2006). For example, in one study over half of the burn injury participants reported experiencing negative interpersonal encounters that included starring, comments, and jokes made by others about their scarring which was thought to create a fear in anticipation of what others might say or how they might react (Bergamasco et al., 2002). In a different study investigating how burn survivors support each other online, Mirivel and Thombre (2010) concluded that, "the emotional impact of having visible scars on one's body leaves its own marks on the spirit" (p. 240). Thus, the assessment of how the body looks, how satisfied one is with the body's appearance, and the impact this has on other important variables has become the focus of most burn research. While this is no doubt true to a large extent, it does not account for discomfort that might arise from the body being exposed to public voyeurism that emerged in the findings from this current research.

Furthermore, coping methods employed within the burn population also suggest that individuals attempt to control the aesthetic consequence of their injury. Consistent with the findings from the current study, avoiding social contact and covering the body have been

identified coping behaviours within the burn injury population (Bernstein, 1990; Fauerbach et al., 2000; Lawrence, Fauerbach, Heinberg, & Doctor, 2004). For example, just as those with visible disfigurements tend to recreate their physical appearance through grooming habits, fashionable dress, facial hair, and increased exercise routines (Bernstein, 1990; Thomas, 1982), Moi & Gjendgedal (2008) found that individuals with burn injuries adapted clothing styles and used make up to cover scars.

These authors framed this behaviour as a form of agency by suggesting the participants found this behaviour satisfying in that they were able to find new ways to overcome the aesthetic consequences of burn injury. Hagger and colleagues (2010) explain these behaviours can be understood as a form of impression construction which refers to the behaviours and strategies used to regulate others' impressions based on appearance such as hair styling, cosmetic use, grooming, dressing, or exercising for weight loss or muscle enhancement. They further posit that Western culture's obsession with physical appearance seems to motivate individuals to control how others see them and attempt to present themselves in a positive light. Similarly, it has been suggested that women with burn injuries avoid or limit certain relational activities, such as sexual intercourse, because they believe their scars to be unattractive (Connell, Coates, & Wood, 2015). From this perspective, avoiding relationality and covering the body may be understood as a response to shame about the appearance of the body and an attempt to mitigate the "aesthetic consequences."

The current study, however, challenges this assumption by suggesting that the appearance of the body and resultant body image dissatisfaction or social strain is not the only distressing aspect of the body. While some of the existing findings described above were replicated in my study with the women expressing apprehension about others' reactions, the narratives also

suggest that it is not only the malicious or hurtful behavior itself that creates discomfort, but that through this behavior, the body loses its privacy and becomes exposed. This study's findings suggest that the appearance of the body is part of the process, in that individuals comment or question the women based on observing their bodies. However, most women did not speak about what their bodies looked like or express dissatisfaction with its appearance. Rather, they focused on feeling bared, like "public property." It is not clear from the findings that the women were dissatisfied with their bodies; but rather, these findings suggest a relational dynamic whereby women feel exposed, not necessarily dissatisfied. Regardless of the assessment of their appearance, the findings reveal that the women felt a loss of corporal privacy that left the body exposed and the women feeling angry. Thus, there appears to be a larger process in play following burn injury in which the body becomes part of the public realm, privacy is threatened, and it is available to be consumed by others. What this research highlights is that there is more than the appearance of the body itself creating distress but that feeling as though the body is losing its privacy as it is exposed to others also creates distress. Thus, other people played a significant role in how most women experienced their bodies, less so than the actual appearance of the body itself.

From this, I argue that hiding and covering the body may also be understood as a way of maintaining the privacy of the body while also regulating the relational tension that created unpleasant feelings such as anger, embarrassment, or awkwardness. By covering, or "becoming invisible" the women prevented or minimized the chances others would comment, reject, or criticize their bodies, thus interrupting the uncomfortable process of being exposed. While this provides some control over the body, it also requires concealing parts of the self by explicitly covering the body. The women tried to be "invisible," or make their bodies less prominent in the

world, in order to regain a sense of privacy. The women sacrificed parts of themselves, they hid

part of their being and denied themselves relational experience, in order to smooth the relational

tension or maintain ease in the relationship. Covering and avoiding may have reduced the

feelings of being exposed but it required them to deny themselves, just as Jack (1991) speaks

about in her self-silencing theory. Resiliency, or struggling with this tension, appears to be a

trade-off process between silencing the self and maintaining relationships which allows the

women to create a world in which they are able to move forward in recovery.

The idea of women's bodies being public is not new altogether with a well-documented

history of women's bodies being publicized, commodified, objectified, sexualized, criticized,

and controlled with a pervasive focus on women's in North American culture (e.g., Bordo, 2003;

Craighead, 2011; Wolf, 1990). Bordo (2003) points out that women's lives are often centered on

the body both with respect to one's own bodily appearance and the caring for other bodies. She

notes,

> for women, associated with the body and largely confined to a life centered on the body
> (both the beautification of one's own body and the reproduction, care, and maintenance
> of the bodies of others), culture's grip on the body is a constant, intimate fact of everyday
> life (pg.17).

Holloway (2011) further explored the focus on women's bodies and examined how women's

bodies are prone to being forced into the public sphere and "denied the presumption of privacy"

(pg.9). She used examples from law and medicine to argue that women's bodies are particularly

prone to "public unveiling" when social discourses emerge about private events of the body like

death, pregnancy, and illness. For instance, when debate emerges regarding the ethics of medical

care such as abortions or the use of selective reduction to choose an embryo to tissue match for a

child with a terminal illness, Holloway argues women's relationship to privacy is compromised

as the body is forced into public discourse. She concludes that women have become accustomed

to having some part of their corporality exposed to public attention. Similarly, Van Der Meer

(2001) uses the example of pregnancy to examine how women's bodies come to be seen as

public property, available to be commented on and touched.

Burn injury, as was revealed in the current study findings, is yet another way women may

be forced in the public realm and experience the loss of bodily privacy. The process of the body

becoming public was explicit with the participants using phrases such as, "public property", "up

for public commentary", "there for everyone to see", "everybody knows", and "completely

exposed" in reference to their bodies. Other times, the process of the body made public was more

subtle in stories that involved situations like medical examinations or sexual encounters in which

women did not use explicit "public" or "private" language but discussed their bodies as exposed

and available for others to observe and potentially criticize. One other burn injury study included

a participant with a similar experience in the context of medical care. In a case study with a burn

injury survivor (Morse & Mitcham, 2010), the female participant reported feeling like she was

treated like "piece of meat" and went on to comment,

> "[y]ou have to flip up your gown so everyone can see and it's just and awful feeling. You
> lose your modesty, your dignity. After a while you don't care, you start thinking of
> yourself like a piece of meat."

This quote is strikingly similar to how some women in the current study spoke about their

bodies. In the quote above, the participant spoke about the consequences of revealing her body

so "everyone can see" just as three of the women did in the current study. The authors of the

earlier study suggested that over time, as one is made to feel reduced as a person through medical

care that depersonalizes the body, one starts to also reduce the self and separate from the body.

Morse and Mitcham argue that the participant dissociated herself from her body using

depersonalize language such as, "piece of meat" in order to separate herself from the pain of

losing her modesty and dignity. Although the women in the current study discussed a similar experience of becoming exposed, the reaction is understood differently. In Morse and Mitcham's understanding, disembodiment, or a detachment from the body occurs when the body becomes public. However, in the current study, I argue that the women fight to protect themselves from this process. In considering both interpretations, perhaps the women in the current study were fighting against the disembodiment Morse and Mitcham identified which may occur when the body becomes public.

In exploring the ways women engaged to counter the body made public process I argue that the women take responsibility for managing the relational dynamic not only to reduce their discomfort as their bodies become public but to maintain the relationship. Bordo (2003) suggests in her analysis of gender, Western culture, and the body, that women's bodies are held responsible for others' reactions. She uses the example of women being blamed, based on the appearance of their bodies, for sexual assaults. In this study, some women remarked at the audacity of others who "think it's okay" to ask about their bodies but fought within themselves to resolve this relational upset. In this respect, women took on the responsibility to smooth over the relational tension in situations in which their bodies became public, in line with Bordo's assertion that women take responsibility for others reactions. Thus, in complex interpersonal situation we see women taking on responsibility through covering, excusing, and avoiding to manage the relational tension that emerges when the body becomes public.

The divided self. Many women also engaged in self-silencing consistent with "the divided self" which refers to a discrepancy between a woman's outer performance and inner emotional self (Jack, 1991; Jack & Ali; 2010). "The divided self" emerged in narratives that involved a relational tension about sharing or inhibiting their burn stories and, thus, maps onto

the *To Share or to Protect* section. Here, the women spoke about storytelling as a form of connecting with others and suggested that it allowed others to better understand them and their experience with burn injury. At the same time, these women acknowledged that in their attempt to connect by sharing their inner experience, others may be impacted negatively and thus, in negotiating this tension, some inhibited storytelling and rather portrayed a happy, unaffected exterior. Inhibiting storytelling is thus another added piece of how women self-silence, which is not included in the original theory.

The significance the women place on storytelling is not surprising considering humans have been described as "storytelling creatures" in that we use stories to make sense of our relationships, establish bonds based on common themes of lived experience, and learn from others (Bruner, 1990; Chin, 2010; Frank, 2009; Kellas, Willer, & Kranstuber, 2011). In this sense storytelling is conceptualized as a relational tool that cannot only organize thinking and help one create meaning of their experiences, but, most relevant to the current thesis, can help reconnect the story-teller to others socially (Niederhoffer & Pennebaker, 2009). That is, research on the importance of storytelling indicates that sharing one's story with another person alerts the other to the storyteller's psychological state, which maintains social ties between the two people and has the potential to transform how individuals understand one another (Pennebaker & Graybeal, 2001; Rudelius-Palmer & Chin, 2006). Similarly, Jack (1991) also found through her analysis of women's narratives that the interactive exchange of speaking with an intimate partner was essential to the women's experience of connection.

If storytelling fosters connection in relationship, it may be particularly important for women. According to relational-cultural theory, women's sense of personhood is grounded in relatedness to others and women tend to find satisfaction, pleasure, worth, and effectiveness

through a sense of connection with others in relationship (Miller, 1986). Relationality, according

to this theory also fosters resiliency through developing mutually empathic and growth-fostering

relationships (Jordan, 1992, 2013; Jordan & Dooley, 2000.). Unfortunately, qualities that foster

the development of close relationships are not valued in predominant models of knowledge

which emphasize separation, individualism, and autonomy. Furthermore, our society does not

support opportunities for most to learn the "relational mode" of interacting (Miller, 1976, 1984;

Jordan, 2013). Thus, women appear to be in a double bind. Their socialization and orientation

towards connection and relationality should, according to prominent feminist theories (Jordan,

1992, 2013; Gilligan, 1982 ; Miller, 1976) help facilitate resiliency; however, at the same time,

this mode of being is not valued or encourage, and can be seen as flawed or weak, thus leading

women away from connection. This dilemma surfaced in the women's narratives as they

struggled to negotiate when to share, and work to develop connection, and when to silence.

     With respect to burn injury specifically, storytelling has received little attention. Badger,

Royse & Moore (2011), advocated for the use of storytelling via written narratives as an

intervention for burn survivors following their text-analysis study of web-based narratives. While

those authors suggested storytelling may allow for emotional processing, insight development,

and facilitate the meaning-making process, the results from this study indicate that storytelling

following burn injury may also work to counter isolation and stigma associated with the injury

by fostering connection and understanding between storyteller and listener. While the beneficial

aspects of sharing explored above are significant and may facilitate recovery, it is not this

simple.

     Despite the benefits of sharing traumatic experiences, research suggests people do not

always tell their stories. Stigmatization, embarrassment, and shame are common reasons people

do not share their traumatic experiences with others (Davison, Pennebaker, & Dickerson, 2000;

Niederhoffer & Pennebaker, 2009). Current findings suggest there may be another reason

individuals chose not to share which involves not wanting to burden others with the emotions of

the traumatic experience. Past research would certainly support the women's concerns that their

burn injuries impact those to whom they are close. In a study designed to understand the lived

experience of patients and families, Gullick at colleagues (2014) concluded that the essence of

the burn injury experience for the patient and family was "paralyzing emotional trauma" and

used the term "vicarious suffering" to describe the experience of family members when they

witness the pain of a loved one. It is here where the tension in the narratives emerged as the

woman struggled to balance the benefits and potential detriments of sharing their stories. There

was an overwhelming sense of guilt and wanting to minimize the effect their injury had on

others, while at the same time a desire to connect through sharing. Norrick (2005) discusses a

similar tension that emerges in the telling of transgressive narratives that may be embarrassing,

scary or inappropriate. He posits that the storyteller must balance the "tellability" of a story and

negotiate the boundary between impropriety and increased intimacy gained by sharing a personal

narrative. His research suggests that people will push the boundary towards increased intimacy

despite the risk of losing face.

    It appears most women in the present study were engaging with a similar boundary

negotiation in a quest for intimacy and connection; however, they did not appear concerned with

diminishing their own embarrassment or fear but were rather concerned about the listener's

experience. In negotiating the tension between the possibility to connect and the possibility to

hurt, many women opted to silence their stories in order to protect the other in what looks like

"the divided self" aspect of self-silencing. The women in this study, in order to protect others,

denied their inner emotional experience of burn injury and their desire to connect through

sharing, by performing a different outer self who does not engage in storytelling about burn

injury. Through inhibiting storytelling, the women could suppress depression, anger, or pain and

rather portray a happy exterior. In my previous research with women with burn injuries (Hunter

et al., 2013), the participants also spoke about protecting significant others from distressing

emotions throughout the burn recovery process by not telling others about their experiences.

Again in the current research, some women attempted to protect others from this impact by

taking on responsibility for others' feelings and silencing their burn stories.

One way the women talked specifically about performing a different outer self was in

stories about humor which emerged as a small narrative thread in the context of storytelling.

Some women identified humor as a coping mechanism or an attitude that help them move

forward in recovery. The use of humor when facing adversity is not new (Kornhaber, Wilson,

Abu-Qamar, & McLean, 2014; Kuiper, 2012; McLean et al., 2015); however, a tension emerged

in the current research as more than one participant alluded to the idea that humor can be used as

a sort of defense mechanism that "masks" other emotions or to communicate well-being, even

when the inner self may be feeling differently, "morose" for example. Communicating well-

being seemed to be important in order to relieve significant others of guilt or the emotional

impact of the woman's injury. With the use of humor, the women were able to tell their stories

without the negative emotion. They could lighten the story to make it digestible for their

audience and maybe even for themselves. Thus, in my discussion of self-silencing, humor

appears to be another way women silence their inner emotional experience for the benefit of

maintaining relationality with significant others.

Once again, as was the case with silencing-the-self, the women negotiated relational tension by engaging in self-silencing. Although this means concealing or inhibiting parts of themselves, it also means they are able to maintain stability and relationality. Building resiliency in this sense appears to be a complex process that is not only positive but includes both inhibiting the inner self while maintaining important relationships.

Care as self-sacrifice. Another dimension of self-silencing identified in the current study was "care as self-sacrifice" which refers to the extent to which an individual puts the needs of others before their own (Jack, 1991; Jack & Ali, 2010). Care as self-sacrifice emerged in the *Accepting Support from Others* section when some women struggled to accept support provided to them following their burn injuries. The women in this study described a tension in which they acknowledged needing, wanting, and enjoying the emotional and instrumental support provided by others, but, at the same time, admonished themselves for being dependent and, thus, at times rejected support. In the present study dependency was primarily constructed in narratives about the physical limitation imposed by burn injury which limited the woman's ability to perform her regular duties of caring for herself and others through completing tasks such as cooking, house cleaning, grocery shopping, and parenting. The loss of the ability to perform the care-taking role thus created a sense of dependency and threatened their familial role as care-taker. In negotiating this struggle of resiliency, I reason that some women sacrificed support in order to maintain their role and independence.

The importance of support from others is well researched with the burn population. For example, having family present during hospitalization has been shown to increase satisfaction with care, improve patient coping, and has a positive relationship with survival rates of those in intensive care (Dahl, Wickman, & Wengstrom, 2012; Muangman et al., 2005). Furthermore,

those who have experience burn injuries themselves have identified a number of social supports

as helpful resources during recovering including family, general medical staff, other burn

survivors, friends, and religious supports (Badger, Royse, and Moore, 2011). Similarly, 88% of a

study sample of burn survivors reported support from family as very important in their recovery

while 65% reported the same for support from the burn team members (Sproul, Malloy, &

Abriam-Yago, 2009). Holaday and McPhearson (1997) research involving a systematic review

of the literature followed by qualitative interviews also highlight support from cultural

influences, community, school, personal, and families as the main factors that stimulate and

sustains resiliency within the burn population.

In addition to finding support beneficial, Moi and colleague (2008) found that a dominant

theme amongst the participants in their phenomenological investigation of burn injury

experience was feeling grateful for the support they received. The current study supports this

finding in that many of the women spoke about the importance of the support they received in

what could be understood as gratefulness. For example, one short quote, "bless homecare, I love

homecare," portrays a sense of gratitude towards burn care providers (which I comment on later

in the discussion). However, the analysis provided in this study suggests that receiving support

following burn injury is a more complicated relational process than what is currently described in

the literature. Specifically, gratefulness is not the singular emotion felt around receiving support

and support may, in fact, conjure less positive feelings such as guilt and a loss of independence.

Existing literature has identified loss of independence as a significant theme following

burn injury (Moi & Gjengedal, 2014; Moi & Gjengedal, 2008; Williams et al., 2003). In a review

of the psychiatric and psychosocial outcomes of burn injury, Defiede and colleagues (2009)

suggest the functional disability caused by burn injury brings up issues related to self-efficacy,

helplessness and dependence, and existential questions of purposeful living. In their book

dedicated to describing the burn injury experience, Carter and Petro (1998, as cited in Moi &

Gjengedal, 2008) indicated that "total dependency" on others was the worst part of the burn

injury experience for many individuals. Past research suggests that individuals strive to regain

their independence following burn injury in order to regain bodily function or maintain their

identity as an independent person. Correspondingly, a study using phenomenology and grounded

theory found that both men and women with burn injuries spoke about loss as a general theme

which included loss of their identity and social roles (Williams et al., 2003). O'Connor (as cited

in Moi & Gjengedal, 2008) suggests that a strong desire for burn survivors to free themselves

from their reliance on others might be understood not only as a way of reducing the strain on

their closest kin, but also as a way of overcoming their own weakness and regaining a sense of

self. Past research, thus, suggests that burn injury results in a loss of role and independence that

may impact one's identity. In the current study, the women's roles as care-takers appeared to be

strongly linked to their sense of independence and, thus, based on past research, perhaps their

identity.

Women's identification with caretaking roles has long been an important topic in feminist

research dating back to 1963 when Friedan wrote about the dissatisfaction women experienced

with their roles as wives and mothers which predominantly involved taking care of others. Half a

century later, researchers find that women still identify with these normative role-identities

(Jacques & Radtke, 2012; Lafrance & Stoppard, 2006). Many argue that taking on the traditional

expectation of femininity that revolves around the caretaking roles of wife and mother puts

women in a disadvantaged position as they place the needs of others before their own and may

experience guilt or are labeled "selfish" if they engage in self-care or health promoting practices

for themselves (Lafrance & Stoppard, 2006). Women in the current study reiterated this attitude in their stories about accepting help that included feelings of guilt when they were not able to fulfill their caretaking responsibilities while healing from their own trauma. McKenzie-Mohr and Lafrance (2011) argue that if there are no counter-narratives available, individuals may rely on inaccurate and harmful master narratives to make meaning. These authors go on to draw attention to the absence of narratives about women's self-interest which they suggest can lead to the silencing of women and contribute to the maintenance of harmful dominant narratives around exclusive care for others. Women in the current study struggled with how and when to accept help from others which may have been, in part, due to the lack of appropriate cultural narratives available about of self-care, reliance on others, and receiving care from others.

Reestablishing one's role in the family by means of sacrifice seems to be how the women in this study regained their identity as independent women and care-providers. Identity has been identified as a significant factor in the process of resiliency suggesting that regaining a sense of self can facilitate positive recovery outcomes. For instance, the degree to which an individual has a coherently defined, internally consistent, and stable identity, has been shown to be positively correlated with coping styles, decision making, and body image while it is negatively correlated with depression and anxiety (Hucker, Mussap, & McCabe, 2010; Lewandowski, Nardone, & Raines, 2010). Moreover in the burn-specific literature, renegotiating the self, or in other words one's identity, by incorporating new characteristic with one's existing understanding of the self is associated with resiliency following burn injury (Lau & van Niekerk, 2011; Morse & O'Brien, 1995). Relationality also becomes an important aspect while discussing identity as having supportive relationships may encourage individuals to make independent decisions which may facilitate a sense of independence (Niemic, Ryan, & Deci, 2010; Willis & Bantum, 2012).

Another way of looking at relationality in this context involves considering how women have been socialized to interact relationally which may impact how women understand the changes in their roles. Jack's (1991) theory of self-silencing, women are socialized to maintain and care for relationships, sometimes at the expense of their own desires or needs in what she labels "care as self-sacrifice." The women in this study identified their own need for support but often relinquished this need in order to ease the burden on others. In doing so they sacrificed, thus, maintaining a care-taking role to some extent. Furthermore, many women spoke about completing acts of care before they were physically ready. In this sense, the women were again sacrificing their own well-being or need to heal in order to relieve the other of the burden of the injury.

Emerging in this study is an exploration of how women respond to the loss of roles they view as defining. We see in these narratives that even when women were struggling with their own trauma and the loss of their roles, which research referenced earlier suggested would create internal conflict concerning identity and self-esteem, the women were, in addition, focused on the impact on others. Just as they were concerned about the consequences their stories might have for others in the *To Share or Protect* section, here, the women were concerned about how their own functional limitations might affect others. Many women identified guilt, an interpersonal emotion focused on transgressing against another, associated with not being able to sustain their care-taking responsibilities. The expression of guilt in care taking situations suggests that the women did not easily forgo their caretaking roles and may have been uncomfortable receiving the level of support required following a debilitating injury. Furthermore, because of the loss of their roles they believed they were putting pressure on their loved ones to pick up when and where they could not perform. Thus, narratives presented in the

current research highlighted the impact of the role change had on other people, as opposed to the impact on the women themselves.

The current study does not address whether support is beneficial but is rather contributes to an understanding about what it is like to receive this support. While the existing literature addresses the significance of social support and the loss of independence associated with burn injury, it fails to consider what these two factors might mean taken together. What this thesis adds to the literature is explicitly highlighting and exploring the tension between needing help – and being therefore dependent on someone– and wanting to be independent –and therefore not needing others. While Moi and Gjengedal (2008) addressed gratefulness for support and a drive for independence separately, research to date has failed to recognize the conflict that may emerge for those who highly value support and identify it as a requirement for recovery but also feel guilt and a sense of dependency. The present investigation illuminates that women may feel conflicted about the support they receive during burn recovery as it threatens their role as care-taker. This suggests that resiliency likely involves an intricate balance between forgoing important roles or one's sense of independence for a time while care can be provided in order to move ahead following trauma. Again, trade-offs and balancing tensions becomes the core of the resiliency process.

Resiliency & Relationality

To conclude, I will bring the discussion back to the main focus of this research by exploring how the main findings contribute to a better understanding of resiliency for women following burn injury. Based on the work of Walsh (2003) and Higgins (1994), resiliency was defined as a process in which an individual engages with a "tension of opposites" to work through an adversity. Therefore, in order to achieve a more holistic view of what resiliency looks

like for women following burn injury, I identified points of tension that emerged in the women's

narratives. The main struggles that emerged in the findings which had two overarching

commonalities: 1) each was highly relational in that the tensions emerged in interpersonal

contexts and 2) each tension involved the women engaging in some level or aspect of self-

silencing. Taken together, the main findings suggest that, for women, building resiliency

following burn injury may predominantly involve working through relational tensions.

Relationality is the extent to which an embodied self psychologically or physically

approaches and withdraws from another embodied person (Radden, 1996). Exploring burn injury

from a relational perspective is unique to the current study; however, the importance of others

following injury has been identified in other work with burn survivors. There is a strong

association between other people and positive recovery experience documented in the burn

literature and resiliency literature alike. Resiliency literature suggests an overwhelming support

for the importance of others when facing adversity such as cancer (Pentz, 2008), caregiver stress

(Wilks & Croom, 2008), arthritis (Smith & Zautra, 2008), PTSD (Boscarina, 1995), and chronic

stress (Sapolsky, 2004), to name only a few. Relationality is, however, more than social support

and emphasizes the importance of the relationships and relational aspects in healing such as

mutual empathy and connection. Furthermore, relationality is focused on negotiating

relationships in terms of physical and psychological proximity to another whereas the construct

of social support is typically more focused on an offering of practical or emotional tasks to help

another person. While the two constructs overlap (and relationality could certainly be part of

offering and receiving social support) relationality is a more complex interpersonal negotiation

than a mere exchange of services.

Walsh (2003) in her paper on the relational resiliency approach advocated for the importance of strong relationships when facing adversity and noted that relationships – including family, friends, mentors, ties to a religious community, or a personal relationship with God – are the "lifelines for resiliency." Relational-cultural theory also highlights the significance of "growth-fostering" relationships in fostering resiliency (Jordan, 1992, 2013). Within the burn population specifically, it has been well supported that other people are a significant factor for positive recovery outcomes. For example, having family present during hospitalization has been shown to increase satisfaction with care, improve patient coping and has a positive relationships with survival rates of those in intensive care (Dahl et al., 2012; Muangman et al., 2005). Additionally, a qualitative study reported participants identified a heightened awareness in relation to family and friends following burn injury while another found participants to feel more connected to important others (McLean et al., 2015; Moi and Gjengedal, 2008). These researchers, however, interpreted the heightened relational awareness as a positive outcome of burn injury in that the participants came to value their relationships or put greater importance on relationships. They, for example, indicated that some of their participants attributed close relationships as the main reason they worked hard in rehabilitation. The present study expands on this understanding and adds complexity to our understanding of relationality following burn injury in highlighting the tension that emerges in interpersonal contexts and framing that experience as an opportunity for resiliency. That is, we begin to see *how* relationships are negotiated within the resiliency process as opposed to simply identifying relationships as a promotive factor that can be included in the long list of variables that contribute to positive outcomes following adversity. That is, we begin to see *how* relationships are negotiated within the resiliency process as opposed to simply identifying relationships as a promotive factor that

can be included in the long list of variables that contribute to positive outcomes following adversity. This way of understanding resiliency may be particularly relevant for women considering the importance of relationality for this population based on socialization and cultural ideals. In contrast to most burn research, this study includes a gendered perspective, allowing for a more nuanced and specific understanding of the experience for women.

While the importance of others after burn injury is certainly supported in the current study's findings, the results suggest it is not this straightforward and that, in fact, relationships may also be difficult following burn injury. Indeed, it is also well documented that individuals struggle with social interaction following burns and that therefore, others can also be a hindrance to the recovery process. Williams' (2003) study about recovery and resiliency following burn injuries highlights the stress burn recovery places on the family relationships, reporting that at times stress can be so great it results in the of dissolution of relationships. Similarly, in a study investigating life impact of burns using quantitative and qualitative methods, 38.6% of participants reported a change in relationships (Ciofi-Silva et al., 2010), defined broadly to include changes in sexual activity, changes in marital relationships, or with other significant people or friends. The existing literature, thus, presents two opposing views of relationships following burn injury. This ambivalence with respect to others' role in burn recovery was the main tension explored in my research which highlighted struggles that emerged within relationality. I argue that engaging with this incongruity, in turn, creates an opportunity to build resiliency as the individual works through the ambivalence created when others are seen as both helping and hindering.

Looking at how women are socialized and taking into consideration cultural expectations using Jack's self-silencing theory may help contextualize the overall findings of this study. As I

explained at the beginning of the discussion, Jack (1991), along with other researchers (e.g.,

Fehr, 1999; Miller, 1976; Radden, 1996), posits that women are socialized to orient their self-

concept around affiliating with and maintaining close relationships. Given the emphasis on

nurturance and care-taking, Jack suggests women have a "health capacity" for intimacy and

closeness which may be viewed as hallmarks for maturity and health. However, she argues the

need or desire for intimacy and closeness are associated culturally with dependency and thus

devalued and held up as weakness. Thus, women often undermine the self with respect to the

level of dependency they may seek in order to appear self-sufficient and independent –culturally

valued characteristics seen as "mature." Overall, Jack concludes that, "[w]omen use the language

of the culture to deny what, on another level, they value and desire" (p.5). Throughout their

narratives women grappled with this tension between what they desired or wanted (to share their

stories, to accept support, or for their bodies to remain private) and what they perceived others to

want or need. From this I propose that the main struggle for resiliency following burn injury for

women lies within negotiating and finding balance between one's own needs and the needs of

others to maintain relationships. Given the importance of relationality for resiliency, and

considering the current study findings suggest women work to negotiate relationality following

burn injury, I suggest that helping women recognize and handle the difficulties faced within

relationships following burn injury is pertinent.

I argue many women in this study employed self-silencing techniques to negotiate the

difficult relational tensions that emerged following burn injury. Given power imbalances in

society, women have limited options, both materially and psychologically, when it comes to

responding to trauma. Considering these constraints and women's socialization as "empathic

nurturers", self-silencing may be one of only a limited number of options available to them in

negotiating relationality after this traumatic event. While the findings do not suggest whether or

not the self-silencing strategies were effective or what the impact it had on the women, the

literature offers some perspective on how self-silencing may impact an individual. There is an

abundance of research supporting the relationship between self-silencing and negative mental

health outcomes. From Jack's perspective, self-silencing is detrimental for women in relationship

in that self-silencing is correlated with depression. Self-silencing behaviours have been shown to

be detrimental to those who engage in them with self-silencing being linked most closely to

depression (Gratch, Bassett, & Attra 1995; Jack 1991), as well cardiovascular disease (Faber &

Burns 1996), and irritable bowel disease (Ali et al., 2000). For example, Cramer, Gallant, and

Langlois (2005) found, through structural equation modeling, that with women, depression was

directly predicted by self-silencing, self-concealment, and self-esteem. Other studies have

reported similar findings with self-silencing promoting depressive symptoms as mediated by

self-concealment and self-esteem (Cepeda-Bonito & Short 1998; Jack 1991; McGrath, Keita,

Strickland, & Russo 1992).

　　　　While self-silencing is a relatively new concept within burn literature, the self-silencing

techniques employed by these women appear similar to an approach-avoidance coping technique

which has been found to be detrimental, measured by greater depressive and posttraumatic

symptom severity, in samples of burn survivors (Andrews, Browne, Drummond, & Wood, 2010;

Fauerbach et al., 2009). Self-silencing goes beyond our traditional understanding of denial or

suppression in that it posits the function of such behaviour is to maintain relationships, as

opposed to, avoiding the experience of negative emotion. Inhibiting thoughts and feelings

following a trauma (such as a burn injury) through lack of disclosure is associated with PTSD,

self-absorption, the need to self-protect, distancing from the caring of others, social isolation

(Niederhoffer & Pennebaker, 2009; Pennebaker, 2000; Roemer, Litz, Orsillo, & Wagner, 2001).

Similarly, Miller (as cited in van Daaleen-Smith, 2008) argues that authenticity, self-

determination, and power are crucial to mental health in that affirmation of emotion is essential

in ensuring women express themselves. Thus, the way women engage in relational tension

following burn injury may impact other outcomes such as depression or posttraumatic

symptoms. Considering women have been found to be at greater risk for depression following

burn injury (Thombs et al., 2007), the current study findings suggest the tendency to self-silence

may contribute to women's risk for depression following burn injury.

        Although developed based on research involving exclusively women, the topic of self-

silencing has more recently been explored with samples of men with evidence that men also

engage in the suppression or denial of one's self, needs, and emotions (Cramer, Gallant, &

Langlois, 2005; Drew, Heesacker, Frost, & Oelke, 2004; Locker, Heesacker, Baker, 2011;

Medved, 2011). Within the burn population, one study concluded that men deemphasized or

ignored emotional and distressing aspects of their burn injury and would "fight" to overcome

pain and physical limitations, thus, suggesting men may have been suppressing parts of

themselves and ignoring their need for support (Thakrar et al., 2015). While the suppression of

self appears to transcend genders, many caution around applying a theory developed based on

women's experiences to men (Jack & Dill, 1992; Remen, Chambless, & Rodebaugh, 2002). One

major distinction between the genders in our understanding of self-silencing is socialization.

While self-silencing as described by Jack (1991) develops for women through socialization that

encourages nurturance, relationality, and closeness in order to maintain relationships,

socialization associated with self-silencing in men encourages direct suppression of emotional

expression through instructions such as "be a man" or "men don't cry" in order to maintain

power in relationships, prioritize their own needs, and maintain a sense of self-sufficiency (Pollack, 1998; Remen et al., 2002; Reubens, 2003). Unlike the research with women, self-silencing in men has not been found to be associated with depression, anger, or loss of self (Duarte and Thompson, 1999). Therefore, it is to be expected that men and women may have similar narratives about struggling to accept support or sharing their stories following burn injuries but the function or reason for silencing may vary by gender provided current standards of socialization. That is to say that while relevant for both genders, self-silencing may have different meanings for men and women and may have different consequences.

One could argue self-silencing was an effective tool in negotiating relational tension which allowed the women to maintain continuity in relationships and facilitated struggling with resiliency. The burn injury changed their relationality with others with respect to their bodies, their valued social roles and identity, and how they connect through stories. In negotiating this new relational space, resiliency emerges as they labor to find a way in the world with which they can live. The women soothed the relationship, kept others happy, diminished the emotional impact, and protected others from the burden of the injury. Thus, they may be seen as having "struggled well" through tensions in relationship. In doing so, they may have silenced their experience and put others ahead of themselves. This does not discount the work they did to negotiate these situations and is a step in moving forward after burn injury. In fact, in the chaos that ensues following trauma, continuity is vital and it may not be the time to challenge the engrained socialization of relational patterns in their lives.

Strengths & Limitations

Limitations. In discussing limitations, it is important to reiterate that qualitative methods do not claim to, or aim to, achieve statistical significance, generalizability, or representativeness.

Thus, the findings from this study may not hold true for all women. Moreover, given the qualitative nature of this study, it is important to note the subjectivity inherent in the study design. Although considered an advantage in qualitative research, the subjective nature of the design means that the findings of this study represent one interpretation of the data. There will likely be several plausible interpretations of the data, dependent on what the researcher brings to the research; this study only provides one such perspective.

The current study was further limited as the participants were not randomly selected but rather self-selected. Thus, participant characteristics may have played a role in the results and self-selection may have influenced the participants that agreed to participate. For example, women who felt as though they were more relationally oriented may have been more likely to participate than those who were organized in a more solitary or introverted manner. Similarly, my study was limited to women who had burn injuries less than 30% TBSA, as it has been shown that larger burns may result in different sequelae and involve unique challenges as compared to less severe burns. Thus, the findings presented may not extent to represent women with larger than 30% TBSA burns. The above noted limitations speak to individual differences of the participants that may have impacted their narratives; and thus, the findings presented are limited by the social locations of the participants. While some narrative threads were presented that appeared to be consistent across all women, it is important to note the individual differences that emerged between participants. Although one strength of the study is the inclusion of a diverse range of women with respect to age, time since injury, and ethnicity, performing a cultural analysis was beyond the scope of the present study but may be relevant, particularly considering the role of self-silencing and emphasis on the body.

Finally, the definition of resiliency used in this study is only one of many definitions currently being used in existing literature. As such, the findings were limited to looking at resiliency from one such perspective. Given a different definition of resiliency –one that does not focus on the struggle inherent in the process, for example– may have rendered different results. Moreover, the diversity within the literature with respect to the definition of resiliency makes it difficult to position the current research within this literature base as it is not clear from one research project to the next whether researchers are defining and discussing the same construct.

Strengths. Despite the limitations acknowledged above, the current study has several strengths. Although qualitative studies do not offer generalizability or statistical significance, findings offer a different kind of knowledge which adds diversity and complexity to our understanding of the research topic. In fact, the qualitative design of this study is the main strength; using two different qualitative approaches strengthens it further. The inclusion of photo elicitation enhances this project as it facilitates the data collection in different settings. Participants were able to record settings, moments, and ideas that are typically not privy to health researchers (Catalani & Minkler, 2010). Photo elicitation also improves upon limitations of traditional narrative interviews in that the use of photographs produced by the participant may facilitate story-telling and offers a familiar starting point for the participant to discuss a difficult topic. At the same time, the semi-structured narrative interviews allowed the researcher some control over the direction of one of the interview by introducing topics relevant in the literature in order to gain the participant's perspective on our current understanding of the phenomenon. Both methods offer the subjective knowledge from those who have experienced burn injury, which deepens our understanding of the phenomenon. What researchers deem important or significant may not be what those who live with and experience burn injury value. Using

qualitative methods allows researchers to perceive the world from an insider's perspective and bridges the gap between researcher and participant (Harper, 2002), which only enhances the literature base. It is the first study, to my knowledge, to employ photo elicitation methodology in burn research and will contribute to a growing literature of qualitative burn research. Through the use of both photo elicitation and semi-structured interviews, the current study shares a voice that is largely ignored in the literature to date which makes this research crucial in developing a deeper understanding of resiliency following burn injury.

Another strength is that I explored women's narratives separately from those of men making this one of the first studies to investigate women's experience with burn injury independently from that of men's. While men's perspectives are equally as important, and explored in other research I am involved in (e.g., Thakrar, et al., 2015), I consider it is essential to investigate the burn injury experience of women separately. The inclusion of only women is purposeful and was guided by the current burn literature and the social constructivist framework of the study. Not only are women under researched within the burn literature, what literature that does exist suggests women face distinct challenges follow burn injury (Klinge, Chamberlain, Redden, & King, 2009; Summer et al., 2007; Thombs et al., 2007; Wiechman & Patterson, 2004). A social constructivist perspective would argue that women construct different meanings and understandings of burn injury than are men. Thus, it follows that in order to explore meaning-making after burn injury, men's and women's experiences should be investigated separately.

This study was further strengthened by the diversity of women that were recruited. I intentionally recruited women from differing race/ethnicities, ages, with varying times since injury, education levels, and incomes in order to gather rich and varied data. Finally,

interviewing each participant twice allowed for data collection over time and allowed for a more complete and comprehensive collection of data. Interviews completed over time permitted the researcher to develop a stronger rapport with each participant facilitating rich discussions and also allowed for follow-up clarification or deepening of previously discussed topics.

Implications

In terms of advancing the burn injury literature, findings suggests that the definitions of body image or importance of appearance for women following burn injury may need to be expanded. Currently, the literature focuses on the physical nature of the appearance of the body following burn injury while women in this study focused on discomfort with their bodies being made to feel exposed and like public property. The important distinction is that women may not only be struggling with the appearance of the body but also with the process of the body becoming public. Alternatively, we may be approaching the investigation of body image dissatisfaction indirectly in that women may not be so focused on the appearance of their body as much as the relational tension created when attention is called to their bodies. The tension in this study was the result of a burn injury but on a broader scale women may experience what we understand currently as body image dissatisfaction when attention is called to their bodies because of weight, size, shape, or other culturally prescribed corporal standards. The current conceptualization of body image following burn injury is shortsighted and does not include the dimension outlined in the current study.

Furthermore, there are implications for the resiliency literature base. Resiliency is a well-studied phenomenon but has come to produce a research base that is varied and disparate, making it a challenge to navigate. The findings provide some direction in terms of what might be important for women facing adversity. That is, the findings suggest that women spend their

resources and place significant value on negotiating and figuring out relationships following adversity. Moreover, how women's unique socialization and status impacts the way in which they navigate relationality was highlighted, demonstrating women may, at times, silence their experience, and thus disconnect in relationships. It is important to note that relationships were significant following a trauma that was not necessarily interpersonal or with direct relational implications. Thus, while my thesis focused on burn injury, women facing a wide range of adversity might also emphasize relational aspects of their struggle. There is strong evidence to suggest that resiliency and relationality are intricately and powerfully interwoven in women's experience of adversity.

The emergence of relationality has clinical implications with respect to psychological intervention and follow up care for women with burn injuries. This is an area that has been identified as needing improvement since it has been shown that burn patients often experience lack of appropriate follow-up and support following burn injury (Dahl et al. 2012; Moi et al. 2008; Moi & Gjengedal, 2014).What I have emphasized throughout this thesis is the highly relational aspect of the women's narratives following burn injury with the narratives revealing several ways in which women may struggle through interpersonal experiences. It follows that, overall, women may need increased support regarding relationships, which is particularly important considering stable social relationships correlate with better psychological adjustment following burn injuries (Kildal, 2003; Patterson et al., 2000; Wallis et al., 2006). The focus of the clinical implication section is to look at ways in which professionals may be able to help women struggle through resiliency.

Interventions that focus on social aspects such as peer support, community reintegration, support groups, and social skills training have been shown efficacious within the burn population

(Klinge et al., 2009; Wisely, Hoyle, Tarrier, & Edwards, 2007) . The highly relational aspect of burn injury recovery that emerged in this study suggests that continuing to develop and implement these interventions is indicated. Moreover, developing interventions focused on one-on-one relationships and identifying for the patient potential hurdles in relationality may be important. Specifically, feminist therapies that are based on relational-cultural theory and focus on the importance of relationships and the relational self for healing, growth, and resiliency may be well suited for this population (Miller, 1976; Radden, 1996; Walsh, 2003). Considering the emphasis on storytelling in the women's narratives, one way interventions could focus on improving relationality might be through fostering storytelling by helping women carve out space to tell their stories. This could involve using visual forms of therapy (Hogan, 2016) in order to facilitate narrative production in a similar process implemented in the present study with photo elicitation or alternatively by having women write their burn injury stories, as suggested by Badger, Royse & Moore (2011). Narrative forms of therapy in a general sense support the idea that sharing stories of illness can be therapeutic (Murray & Sargeant, 2012). More specifically, narrative therapy as described by White (2004) suggests thickening narratives that highlight what the patient values in life despite the trauma they have endured in order to revitalize a "sense of self". These approaches support women in the creation and practice of their narratives. In doing so, these therapies may help women find their voice which may reduce the need to self-silence during recovery and thus mitigate the potential detrimental consequences of such a relational dynamic.

Exploring the findings of this gendered study from the relational perspective, I argued that self-silencing allowed the women to negotiate or work through the difficult relational tensions emerging after burn injury. Considering self-silencing is grounded in cultural

understandings and expectations, being mindful and even challenging deep and underlying assumptions about one's role and relational interactions may be helpful for women following burn injury. Just as Partridge (2005) suggested that cultural values around beauty are reevaluated by individuals with burn injury during the final phase of recovery, perhaps engaging in a similar process with respect to cultural values around relationality would help facilitate resiliency for women. For example, challenging one's beliefs and societal expectations about support and dependency may be indicated following burn injury. However, timing of such intervention would likely be crucial since it appears women use self-silencing in resiliency. Taking away or challenging a coping tool would likely not be productive in the midst of trauma or recovery but may be significant later on. For instance, Partridge's model suggests cultural values are challenged in the final stage of recovery and years following the injury. Thus, self-silencing may, in one way, allow women to move forward in recovery, but, in the long-term, may need to be challenged to further promote the resiliency process.

What is more, minimizing the extent to which women feel their bodies are made public following burn injury is imperative. The process of the body becoming public is likely profoundly cultural, engrained in social standards and socialization. Thus, making recommendations that would promote societal change is beyond the scope of this paper and my area of expertise. However, one way the women in this study felt their bodies were made to feel public was in the context of medical appointments. Looking at the current medical practices and the way in which we communicate with women following burn injuries may, in one context, mitigate the larger process at play in which they feel exposed and vulnerable. For example, providing women with adequate coverage for their bodies during medical procedures and ensuring they are comfortable with the environment is imperative to help mitigate the process of

the body becoming public. Furthermore, being mindful that women may feel particularly

vulnerable and wary of questions and comments (even when they may appear to be supportive)

may help professionals communicate in a ways that recognize women as people, as opposed to

only a body. For instance, questions that pertain to how the woman is recovering holistically, in

contrast to focusing on the burn or the body, may help alleviate the sense that the body is made

public following burns.

These recommendations are in line with an emerging practice called *narrative medicine*

which Charon (2006), a pioneer of this field, defines as clinical practice strengthened by

narratological knowledge of what to do with patients' stories –that is, how to listen, absorb, and

interpret illness narratives. Charon explains that within this narrative medicine framework, the

body is viewed as the locus of the self, and thus, healing, prodding, touching, and interfering

with the body is to do the same to the patient's self. She, thus, encourages health professionals

to, "competently and naturally absorb, recognize, interpret, and comprehend the value of all that

patients tell" in their illness narratives in order to better understand the "plights of the patient"

more fully by naming the suffering, offering empathy, and presenting as someone who listens,

cares, and recognizes symptoms (p. 103). Special attention to the narratives burn patients tell and

mindfulness about the connection between the body and self which is advocated in narrative

medicine may be particularly significant in burn care considering the trauma the body has

already endured and the potential for a sense of exposure following the injury identified in this

study.

Future Directions

Self-silencing is only emerging in the burn injury literature and requires further research.

Investigating the extent to which self-silencing occurs within the burn population, particularly

with women, is the next step in developing this area. Stemming from that research, investigating the extent to which self-silencing impacts resiliency may be indicated. More specifically, in the section about accepting support, the women, at times, easily shared and accepted support from family, friends, and health professionals alike; but, at other times, did not feel comfortable accepting the same help. The current study does not address how the women figure out who and when to accept support from others. Further research should attempt to disentangle the complicated decision-making process involved in accepting support. Similarly, in the sharing section, it is not clear from the findings how women chose who to protect and when from the potentially negative effects of storytelling. There was, however, an emerging trend that the protecting behaviour mostly happened within familial relations whereas openness to sharing seemed to emerged particularly outside the family unit. From a relational perspective this could be due to the increase consequence if relationality was threatened by sharing. Self-silencing is thought to protect women from rejection or dissolution of relationship. In this sense, the more important the relationship may result in a greater need to protect. Further investigation regarding women's propensity to protect in the context of relationality may help provide insight into self-silencing following burn injury.

There were several themes identified in the findings sections that were not explored further in the discussion because they represented small or singular narrative threads; they do, however, warrant further investigation in future research. In the body made public section, some women identified their experience of touch to be healing. This is an interesting contrast to the narratives about covering the body and feeling exposed. Further exploration of the nuances of women's experience when others touch their burn injuries is indicated as it may have implications with respect to the conceptualization of the body following burn injury or may be an

area to develop pertaining to mental health interventions. In this same section, I called attention

to the intersection between pre-existing body image issues and burn injury body dissatisfaction.

Preliminarily results from this study suggest that pre-existing body image dissatisfaction may

actually mitigate body dissatisfaction post-burn as the burn injury may seem inconsequential

compared to pre-existing body concerns. Considering the significance of body image not only in

the burn injury population but for women in general, studying the relationship between

preexisting body image and post-burn body image is pertinent.

　　　Finally, the disorder and confusion present in resiliency literature needs to be addressed.

Throughout this thesis I have highlighted incongruence in researchers' understanding and

approach to studying this complex topic. During this study, I struggled with the definition,

conceptualization, and utility of this term. The important distinction that provided clarity was

that resiliency is *not* an outcome but a process—the process of struggling with adversity.

However, while adopting this understanding in theory, researchers seems to have failed to shift

perspectives when it comes to research design considering the literature remains focused on the

individual factors that contribute to positive outcomes. One question remaining is whether

resiliency is dependent on positive outcomes. For instance, if an individual engages in the

process of resiliency—in that she struggles with the "promotive factors" that foster resiliency—

but does not experience positive outcomes, is that individual still resilient? I would argue that

indeed that individual worked to be resilient even though they might not, on any measure of

"positive outcomes" appear to "be resilient". However, the individual is resilient if resiliency is

defined as a process. From this, I posit that our assessment of resiliency should not depend on an

outcome but on how the individual engages with the adversity. For example, researchers may

assess whether an individual facing adversity attempted to foster connection in relationship,

sought out social support, or utilized assets and resources available to them. Further research, discussion, and theoretical knowledge production is certainly required in order to better elucidate our understanding of resiliency.

Conclusion

The overarching aim of this research was to advance the understanding of burn injury rehabilitation and resiliency through the exploration of tensions and ambivalence in women's narratives. I outlined three objectives for this research at the outset of this thesis. The first objective was to understand burn injury recovery through the exploration of women's multiple and varied narratives; the second was to explore areas of tension that might represent the resiliency process; and finally, the third objective was to advance the understanding of burn injury rehabilitation by providing a more holistic view of the resiliency process for women. All these objectives are in fact inter-related and addressed throughout the thesis. Emerging from the participants' stories were three main struggles of resiliency which all revolved around negotiating relationality and included 1) *The Body Made Public*, 2) *To Share or to Protect*, and 3) *Accepting Support from Others.* Through identifying these tensions which were constructed about interpersonal experiences, I suggested negotiating relationality may be pertinent for women in building resiliency following burn injury and indeed burn injury rehabilitation and recovery involves navigating complicated relationships. The women in this study shared their stories and provided a voice that was largely underrepresented in the literature in order to contribute to a better understanding of a complex and traumatic event. From this, we see that fostering resiliency in women following burns is multifaceted and includes potential for challenging deeply engrained societal values, helping women find their voices in relationships, and providing safe and accepting space to share their stories.

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Appendix A: Participant Information and Consent

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Life with a Burn Injury: Images and Narratives from Women

Principal Investigator:
Tevya Hunter, M.A., Ph.D. Candidate
Department of Psychology
University of Manitoba
Phone:
Email:

Co-Investigator:
Dr. Maria Medved, Associate Professor, Department of Psychology, University of Manitoba
Dr. Sarvesh Logsetty, Associate Professor, Department of Surgery, University of Manitoba
Dr. Diane Hiebert-Murphy, Associate Dean, Faculty of Social Work, University of Manitoba
Dr. Jitender Sareen, Associate Professor, Department of Psychiatry, University of Manitoba

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family, or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

<u>**Purpose of Study**</u>
The purpose of this research study is to explore the way in which women discuss their burn injury and how it affects important areas of one's life. Specifically, areas of interest are how women understand resiliency and distress in the context of their injury. Ultimately, results from this study will be shared with the professional community through publication and conference presentation in hopes that the results may facilitate a better understanding of the implication burn

injuries have for women. However, your personal identity will not be revealed. A total of approximately 15 participants will participate in this study.

<u>**Study Procedures**</u>
Women who are at least 18 years of age and have suffered a burn covering between 1 and 30% of their body can participate in this study. If you agree to participate in this study, you will be interviewed on two occasions at the location of your choice (e.g. your home, the burn clinic at the Health Sciences Centre, or at the University of Manitoba Fort Garry campus).

Participation in this study includes the following procedures:
a) you will be asked to answer some demographic questions (e.g. age, education, work history)

b) your medical chart will be reviewed to obtain information related to your burn (exact size of your burn, severity of your burn, location of burn)
c) you will be asked to take photographs in your daily life that pertain to your experience with burn injury
d) you will be asked to partake in an interview, lasting approximately 1 hour, in which you will be asked to discuss between 5-10 photographs you took
e) you will be asked to partake in a second interview, lasting approximately 1 hour, about your burn injury. For example, you will be asked how you feel your burn injury has affected your perception of your body and how this has affected your life
f) you will be asked to complete 3 brief psychological questionnaires

This information is summarized in the chart below:

Activity	Length of activity	Timeline
Demographic Information & Chart Review	10 minutes	Beginning of study
Take photos	Dictated by participant	After recruitment and informed consent
Individual Interview 1	Approximately 1 hour	After photos are taken
Individual Interview 2	Approximately 1 hour	approximately one month after interview 1
Complete psychological questionnaires	Approximately 30 minutes	At the time of individual interview 2

After the study is explained to you and you agree, in writing, to participate, you will be asked to provide demographic information, your chart will be reviewed, and you will be instructed about the photo elicitation process. You will be asked to take photographs in your daily life pertaining to your burn injury and recovery. You will be given your choice or either an SD card to use in your own digital camera or you will be given a disposable camera. Should you chose a disposable camera, you will also be given an addressed and stamped envelope to send the camera to study staff who will develop the photographs for you. In the first interview, you will be asked to tell the story of the photographs you took in your daily life. Additional questions may involve elaborating on what the photograph means to you or why you took the particular photograph. In the second interview, you will be asked questions pertaining to your experience with burn injury including questions like: Is there something you wish other people understood about your injury? What is it like to have others see your burn? Has there been a time you surprised yourself with how well you were doing? Additionally, after the second interview, you will be asked to complete 3 psychological questionnaires about distress, resiliency, and self-silencing. The interviews will be audio-recorded and field notes will be taken to capture additional ideas or details not recorded via audio.

The researcher may decide to take you off this study if you become extremely psychologically distressed. You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

Feedback regarding the study will be provided following your participation. If you would like to receive a summary of the study results, please leave your contact information with us and we will send you this information when it becomes available (approximately Fall 2014)

Risks and Discomforts

You may feel distressed during the interview when discussing your burn injury. It is therefore important to note that you need only discuss the information you feel comfortable sharing and you have the right to not respond to any question and may stop participation at any time with no consequence. Should you feel distressed during the interview, appropriate medical or psychiatric consultation will be arranged and you will be provided with a list of community mental health resources.

Benefits

There may or may not be direct benefit to you from participating in this study. However, some burn patients have found participation in other studies beneficial through sharing their experiences and you may find participation interesting. We hope the information learned from this study will benefit other people with burns in the future.

Costs
All the procedures, which will be performed as part of this study, are provided at no cost to you.

Payment for participation
You will be given $20.00 gift card per interview visit. You will receive this honorarium before each interview visit begins.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. Please note that we are required to report instances of previously unreported abuse involving children other than yourself (i.e., persons who are still minors) or of yourself if you are judged as a vulnerable person, and situations in which you are judged to be a danger to yourself or others.

Raw data will be identified by subject number only (names will not be used). All identifying information (e.g. places, names, etc.) from the interview will be deleted from the audiotapes and will not be transcribed. Data will be kept in a secure office to which only the research team will have access. Data, including audiotapes, will be kept for 7 years after completion of all phases of the study and will be destroyed by June 2020.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study
Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Medical Care for Injury Related to the Study
You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

Questions
You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the study doctor and the study staff: Tevya Hunter at (204) 480-1026
For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Health Research Ethics Board Office at (204) 789-3389

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent
I have read this consent form. I have had the opportunity to discuss this research study with Tevya Hunter or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study, Yes _   No _

Participant signature_____ Date _____

                                                           (day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ Date _____

                                                           (day/month/year)

Signature: _____

Role in the study: _____
Relationship (if any) to study team members: _____

Summary of Results:
If you wish to receive a summary of the results once the full extent of the study has been completed, please indicate such below and provide the best means by which you can be reached. We expect that this will be in approximately one year.

Circle: YES I would like to receive a summary of the results.
                 NO I would **not** like to receive a summary of the results.

If you circled YES, please identify the address of the best means by which you can be contacted:

- Email:
      Name:
      Email Address:

- Letter Mail:
      Name:
      Street Address:
      City:
      Province:
      Postal Code:

Future Research:
If you wish to be contacted regarding a follow-up study in the next year, please indicate below:

Circle: YES I would like to be contacted regarding participation in a follow-up study
                 NO I would **not** like to be contacted regarding participation in a follow-up study

If you circled YES, please identify the address of the best means by which you can be contacted:

□ Same as above

- Email:
      Name:
      Email Address:
- Surface Mail:
      Name:
      Street Address:
      City:
      Province:
      Postal Code:

Appendix B: INVITATION TO PARTICIPATE

Phone Script:

Hello,
I am calling from Dr. Logsetty's office. He is part of a research project investigating how women understand recovery and resilience in the context of burn injury. I am contacting you today to ask whether you would you be willing to be contacted by the main researcher on this project to learn more about the study and to discuss participating in the study. Saying "yes" right now does not commit you to participating in the study; it only means Ms. Hunter will contact you via phone to explain the study so you can decide whether it is something you would like to participate in.

If "no": Thank you for your time.
If "yes": Excellent. When is the best time for Ms. Hunter to contact you and at what phone number?

In-person/Follow-up phone call

Hello,
        My name is Tevya Hunter and I am a researcher from the University of Manitoba. Dr. Logsetty has informed me that you may be interested in participating in a research study about women and burn injury. I would like to tell you a bit about the study, is this OK?
        The purpose of this research study is to explore the way in which women discuss their burn injury and how it affects important areas of one's life. Specifically, areas of interest are how women understand resilience and distress following burn injury. Ultimately, results from this study will be shared with the professional community through publication and conference presentation in hopes that the results may facilitate a better understanding of the implication burn injuries have for women. However, your personal identity will not be revealed.
        To participate, we are looking for women over the age of 18 who have burns covering between 1 and 30% of their body. Your participation will involve taking photographs in your daily life and then participating in two, audiotaped interview, lasting approximately 1 hour each. In the first interview, you will be asked to tell the story of the photographs you took in your daily life. Additional questions may involve elaborating on what the photograph means to you or why you took the particular photograph. In the second interview, you will be asked questions pertaining to your experience with burn injury including questions like: Is there something you wish other people understood about your injury? What is it like to have others see your burn? Has there been a time you surprised yourself with how well you were doing? Additionally, after the second interview, you will be asked to complete 3 psychological questionnaires about distress, resilience, and self-silencing. The interviews will be audio-recorded and field notes will be taken to capture additional ideas or details not recorded via audio.

Do you have any questions?

Would you like to participate? [If, no] Thank-you very much
[If, yes] That's great. Perhaps the best way to explain it further is to go over the consent forms. I will go over the consent forms with you and answer any questions before you sign the forms.

Appendix C: Socio-demographic Questionnaire

Demographic and Medical Information

Demographic Information:

Participant #:

Age:

Cultural Background:

Relationship Status:

Work History:

Education:

Return to Work:

Medical Information:

Date of Injury:

Age at Injury:

Size of Burn:

Location of Burn:

Hospitalization Duration:

Psychiatric and Other Relevant Medical Hx:

Appendix D: Photo Elicitation Interview Prompts

Photo Elicitation Interview Prompts

Tell me the story of this picture

>Why did you take this picture?

>Why did you choose this picture?

>What is represented in this picture?

>What does this picture mean to you?

Appendix E: Semi-Structured Interview Schedule

Semi-Structured Interview Schedule

1. Can you tell me what happened to you? How has it been since?

2. What has been the most difficult part of dealing with your burn?

    a. Can you tell me about a time that you were upset by your injury?

    b. Can you tell me about a time you felt discouraged during your experience with the burn injury?

    c. Tell me the story of your hardest day following your injury? How did you overcome the difficulty?

3. What is it like to have others see your burn

    a. What is it like to be in public?

    b. What is it like to be around: a) Family b) friends c) your partner/intimate relationships?

4. Is there something you wish other people understood about you or your experience?

    a. Are there parts of your experience you have a hard time understanding?

5. Sometimes people find it difficult to talk about their burn. Why do you think that is?

    a. How is it for you?

    b. Are there people you can talk to?

    c. Are there things that are hard to talk about?

6. Some people find themselves depressed or anxious after such an injury. Is that the case for you? If yes: tell me about it. If no: how do you think you've avoided this?

    a. What causes this?

    b. How do you deal with this?

7. Some people find themselves dissatisfied with the way they, or the burn, looks. Is this the case for you? If yes: Tell me about it.

8. Where/how do you find strength? What has helped you in your recovery?

   a. Can you tell me a time you felt good about your recovery?

9. Has there been a time where you were surprised at how well you were doing?

10. Are there certain areas of your life in which you feel as though you are doing particularly well?

11. What would you want other burn survivors to learn from your experience?

12. Is there anything else that you would like to talk about?

   a. Is there something I should be asking in these interviews that I don't cover?

Appendix F: Photo Elicitation Information for Participants

TIPS:

1. Inspiration: what does burn injury mean to you? What was important to you in your recovery? Capture this in your pictures
2. Take pictures of your daily life
3. What have you not noticed? What does participation in this study reveal?
4. Take pictures of things that inspire you
5. Take pictures of things that make you emotional
6. Take pictures of things that make you feel resilient
7. Take pictures of things that make your life difficult

Do:
▶ get verbal permission from others to take pictures of them
▶ explain why you are taking the pictures
▶ get verbal permission for parents when taking pictures of children
▶ permission not necessary if people are not recognizable in the photo

Don't:
▶ Go anywhere or do anything you would not normally do
▶ Forget the goal is to share ideas, not to upset people with the photos
▶ Take pictures of things that are "private" – for you or others

Why use photo elicitation?

Photo elicitation allows you to take pictures of your life with a burn injury. In terms of research, gaining information in different ways allows for a more complete understanding of the topic. Also, it can be hard to express our experiences in words; pictures, as they say, are worth a thousand words. Collecting data using pictures gives us a deeper understanding of an issue that is important to you as a person with a burn injury and for us as researchers.

What will happen to pictures?

We will ask that you choose 5-10 pictures to bring to the interview. We will use these pictures to guide the interview. We will save copies of your pictures but you are also welcome to have copies of the pictures.

What if I have problems?

If you have questions about the process or have any difficulty taking pictures, please contact:

Tevya Hunter
Phone:
Email:

What if I have concerns about how this study is being conducted?

Contact the University of Manitoba Bannatyne Campus Research Ethics Board at: 204-789-3389

Version 1: May-30-2013

What is Photo Elicitation?

Photo elicitation is a research tool used to collect data which emphasizes the participant's viewpoint. In this study, you will be asked to take pictures of important parts of your life with a burn injury. We want you to have the freedom to take pictures that are meaningful in YOUR life. Pictures might be of difficulties you face because of your injury. Or, pictures could be of people, places, and things that were important in your recovery. The options are limitless and up to you!

For a better understanding of this research approach, check out:

http://www.youtube.com/watch?v=X8ISw5Cdi8k

This video captures the spirit of photo elicitation. The projects are about different topics but give you an idea of what this research project is about. We want to know about your life with a burn injury. What it means to you? What it looks like? What inspires you? What makes you resilient? What brings you down? What upsets you? What is your story!?

Appendix G: Script for Photography Instructions

Instructions for Taking Photos

The following script will be used to explain instruction for taking photos to the participants:

The purpose of this portion of the study is to gather information via photographs of what life is like with a burn injury. What we'd like you to do is take pictures in your daily life of things, people, or places that are significant to you. Be creative. Have fun with it. You might take pictures of people that helped you in your recovery, of places you went for support, of the burn itself, or of things that remind you of your burn or your recovery. Photos could also be of difficult aspects of burn injury, things you struggle with, or situations that make you uncomfortable. Do not feel limited to these suggestions. We want to understand *your* experience through these pictures. We want the insider's perspective. Please see the brochure on *photo elicitation* for more guidance on picture taking, ownership of photos, and photographic consent.

Do you have any questions?

Appendix H: Photographic Consent & Waiver

Photograph Waiver

I consent to the use of my photographs as part of the research project entitled *Life with a Burn Injury: Images and Narratives from Women,* which is being conducted at the University of Manitoba.

In addition, I hereby give my permission to make copies, in whole or in part, of my photographs. I agree that the research investigator has all rights to use these materials and has all intellectual property rights in them. I also give up my right to inspect or approve these photographs or any captions or text that may be used with them, or to approve the use of these materials.

I understand that this research will be made available online, in print, and made public at research conferences. In addition, should I wish to have my photographs removed from this research project, I understand I am to contact Tevya Hunter at ███████████████████

I agree that I shall have no claim against the University of Manitoba or against anyone accessing this research product, whether online, in print or by any other means.

I confirm that I am over 18 years of age and that I have not given anyone the exclusive right to use my photographs.

Name (print in block letters): _____

Signature:_____

Date: _____

Appendix I: Transcription Conventions

[ ]	Start and end of overlapping speech
(1)	Pause in seconds
(.)	Micro-pause
((Text))	Transcriber's comment
<u>Underlining</u>	Emphasis
CAPITALS	Speech that is louder than surrounding speech
-	Utterance interrupted
Italics	Increase in pitch

Note. Based on Medved & Brockmeier, 2004