Burn Injury and Self-Silencing: A Study of Women's Narratives

by

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Abstract

Due to medical advances in burn care, the survival rate of individuals with serious burns has

significantly increased. This has lead to a great need to focus on psychological aspects of burn

injury recovery, particularly how people adapt to their changed bodies. The literature indicates

that burn size and severity is not directly associated with the degree of distress and that for

women, dissatisfaction with their bodies increases in the year after injury. In this study, women's

experiences of their bodies were investigated by asking them about pain, social relationships,

mental health, and appearance. In-depth interviews were conducted with female burn survivors

in the first year after injury and the transcripts were analyzed using a narrative-discursive

analytic methodology. On the surface, the women told narratives which emphasized how well

they were doing, however, further analysis revealed subordinate narratives which indicated body

dissatisfaction and difficulties with adjustment. In order to suppress narratives of distress, the

women engaged in "self-silencing," of which three forms are outlined. The self-silencing

functioned to help the women resist the cultural devaluing associated with "disfigurement" and

more personally, to maintain close relationships. As self-silencing has been linked to depression

and anxiety, encouraging women to discuss their difficulties may prove to be pertinent in

psychological adjustment following burn injury.

Keywords: burn injury, women, body image, self-silencing

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Burn Injury and Self-Silencing: A Study of Women's Narratives

Burn injury is a major cause of permanent bodily harm with approximately 5,000 patients hospitalized in Canada each year due to traumatic burn injury (Snelling, 1995); of these 5,000 patients, twenty-five percent are estimated to be female (Thombs, Bresnick, & Magyar-Russell, 2006). Although burns are not the most common form of traumatic injury, they are often rated as more severe than other traumatic injuries (Canadian Institute for Health Information, 2006). Despite these statistics, burn injury survivors have received relatively little attention from researchers looking at traumatic life events (Fauerbach, Richter, Lawrence, & Bryant, 2002). This is surprising considering burn injuries rank fifth among major causes of death for persons aged fifteen to fifty-five years (Wikehult, Hedlund, Marsenic, Nyman, & Willebrand, 2007) 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 et al., 2007).

Existing studies have primarily focused on burn severity and location when investigating psychological consequences; however, various researchers (e.g., Lawrence et. al., 1998) have called into question the validity of these studies suggesting that perhaps *subjective* interpretations of one's body is pertinent in psychological adjustment. This question of validity has been brought forth because burn severity and site are unable to account completely for the degree of psychological adjustment post injury (Fauerbach et. al., 2002). Thombs et al. (2008) found that the subjective measure of body image dissatisfaction appears to be a moderating factor in the development of psychological outcome and was found to be the most salient predictor of psychological function 12 months post burn injury (Lawrence, Fauerbach, & Thombs, 2006a; Thombs et al., 2008). This would suggest that it is important to consider patients' interpretations of body image and how they understand and make meaning of their injury. Furthermore,

exploring the implications body image (dis)satisfaction has on other important areas of functioning such as mental health, social interaction, and pain, is imperative when addressing burn rehabilitation.

There are ample studies investigating the concrete variables of burn injury but there is little information about the patient's perspective specifically. Narrative research is an excellent method to study people's experiences after a traumatic injury because when people are faced with unexpected or unwanted life events, they are forced to create new stories, or narratives, about themselves and their newly conceptualized self. The patient's stories are important because the development of narratives is a basic tool people use to make sense of their experience (Kleinman, 1988). For example, what people tell others, and themselves, depends on how they interpret and understand their experience and their role within the experience (Medved & Brockmeier, 2008). Narrative research captures the detailed stories of life experiences from a small number of people and subsequently analyzes the stories, organizing them into a comprehensive framework that outlines themes throughout the narratives (Creswell, 2007).

Furthermore, examining cultural narratives is a unique way to approach the complex issue of burn injury. It is important to take the broader cultural narratives regarding burn injury into account as people may create narratives in relation to these cultural narratives. Bamberg (2004) explains that cultural narratives regarding specific phenomena are often simplistic and do not hold true for individual experiences. By presenting one's own stories regarding his or her experience with a specific phenomenon, he or she may work at countering the stereotypical cultural narrative. Bamberg suggests that use of counter-narratives, to resist cultural narratives, are guided by concerns about power and hegemony. Thus, how women accept or reject the

cultural narratives that suggest they are devalued in a cultural context will be explored and discussed.

Cultural Burn Narratives of Bodily Change: "You put on your face to face the world"

How do we, as a collective culture, picture someone who has been burned? The cultural macro-narrative regarding burn injury is one of disfigurement, disability, and mental illness. This narrative is perpetuated in the media, socially, and is particularly common in research. Literature on burn narratives depicts the recovery process as a difficult struggle endured by burn survivors at the expense of their relationships, employment, and self-identity (e.g., Williams, Davey, & Klock-Powell, 2003). Although difficult to cite, as there is little published work illustrating this storyline, burn survivors are often depicted as suffering terribly from their painful and disfiguring injury. Although this attitude is supported in the literature, that is, burn survivors do suffer psychologically and physically, this attitude has negative implications for this population. For instance, community psychologists posit that people internalize cultural narratives that have been imposed on them which may lead to psychological damage (Nelson & Prilleltensky, 2010).

Considering the assault to the body caused by burn injury, the cultural narrative regarding beauty and scarring is particularly relevant to female burn survivors. Culture's grip on women's bodies is a constant, intimate fact of everyday life because women are very often associated with the body and thus largely confined to a life centred on the body (Bordo, 1993). Accordingly, women experience great pressure to maintain acceptable appearances, live up to narrow judgments of female attractiveness, and meet standards of "physical perfection" (Gill, 2007). However, the majority of women do not (and cannot) meet the standards presented as ideal, leaving most women discontent with low body-esteem (Brannon, 1996). In fact, it was reported

that 90-95% of American women feel that they do not measure up physically to current social standards (Brannon, 1996), ultimately resulting in low body esteem.

Although the feminist movements of the past have brought women priceless advancements, rights, responsibilities, and freedoms, there remains a power imbalance between the sexes in our culture. A recent wave of feminists are speaking out against the repressive cultural narrative about female beauty. For example, Wolf (1991) argues that the importance placed on female beauty has replaced the oppressive importance of domesticity in social control of women and further comments, "[m]ore women have more money and power and scope and legal recognition than we have ever had before; but in terms of how we feel about ourselves *physically*, we may actually be worse off than our unliberated grandmothers" (p. 10). This 'beauty myth' is perpetuated in the current cultural narrative evident in advertisements, television, films, and Hollywood gossip; North American culture is inundated with images of female beauty and perfection (Farvid & Braun, 2006; Gill, 2008).

Cash (1996), an expert in body image research, argues that body image dissatisfaction develops within a cultural context that emphasizes the value of an attractive appearance; a value that is reinforced by the media and is particularly pertinent for women in North America. In fact, appearance standards in North America are stricter for women and therefore women tend to have lower body image than men (Lawrence, Fauerbach, Heinberg, et al., 2006). For example, Lawrence, Fauerbach, and Thombs (2006b) found that although men tend to report themselves as less attractive, they are generally more satisfied with their own appearance than women. Therefore, there is a disconnect between attractiveness and body esteem; in a contradictive way, women judge themselves as attractive but are still dissatisfied, leaving women with poor body image satisfaction. Similarly, in Tseëlon's (1995) book about femininity she proclaims that,

"looks are important but inconsequential for the man, but they are a defining feature for the woman: both in terms of how others respond to her and how she experiences her own self" (p. 78).

Body Image

Body image, sometimes referred to as body-esteem, describes a person's inner representation of his or her body with respect to cognitive and emotional attributions which becomes an inner working model that is constantly adapting to internal and external information about the body (Andersen & LeGrand, 1991; Bitzer, Platano, Tschudin, & Alder, 2007), which may become integrated into self identity. An extension of body image is body image dissatisfaction which is defined as deviant perceptions, feelings, and beliefs about one's body (Andersen & LeGrand, 1991) and is hypothesized to be relevant to psychopathology (depression, anorexia, and bulimia), physical attractiveness, sexual dysfunction, pain, and physical illness. People with body image dissatisfaction may avoid social situations, self-exposure, and engage in body checking behaviours, excessive grooming, reassurance seeking, and excessive comparison (Lawrence, Fauerbach, & Thombs, 2006a), all potentially leading to decreased quality of life.

Although the literature base on body image dissatisfaction is quite extensive, it focuses primarily on weight and size with little attention paid specifically to "disfigurement" or rather, sudden changes in appearance; consequently, little is known about the course of body image dissatisfaction (or satisfaction) following disfiguring injury (Lawrence, Fauerbach, Heinberg, et al., 2006). Burn injury is a major cause of change in appearance and is thus an important area of research for body image dissatisfaction literature. Even after reconstructive surgeries, burn patients often have a non-typical appearance (Lawrence, Fauerbach, Heinberg, et al. 2006). For example, burn patients will often have dressings or pressure garments up to 2 years post injury

(Selvaggi, Monstrey, Van Landuyt, Hamdi, & Blondeel, 2005). As well, they most often have visible scarring which leaves skin with darker pigmentation and contours that are raised and irregular (Fauerbach et al., 2002). Selvaggi et al. (2005) reviewed patients during burn rehabilitation and found that as burn patients continue to heal, self-image issues intensify because they are exposed to the public and consequently have to renegotiate social situations with a changed body image. Additionally, these authors found that burn severity does not correlate with body image; thus, most burn patients, regardless of burn severity, experience body-image concerns during rehabilitation.

Body image dissatisfaction following burn injury appears to be a particularly pertinent issue for women; this is not surprising considering that throughout history women have experienced social pressures to maintain acceptable appearances (Weitz, 2003). Women's low body-esteem has become so prominent in North American culture that it has become normalized, that is, through interviews with young women, Budgeon (2003) concluded that women live with a constant sense that their bodies need improvements and found that having a problem with the way one looks was interpreted as quite normal. It is argued that this normalization and the growing trend of having appearance enhancing surgery increase the pressure on people with nonnormative appearances to have typical appearances (Rumsey & Harcourt, 2007). This pressure is evident in the burn population in that women represent 46% of patients receiving reconstructive surgery following burn injury (Thombs et al., 2007), when they only represent 25% of the entire burn population. Furthermore, Thombs et al. (2008) found women to be far more dissatisfied with their appearance following burn injury, as compared to men, based on the Satisfaction with Appearance Scale. The results of this study are represented in Figure 1 which depicts increasing dissatisfaction with appearance for women, but not for men.

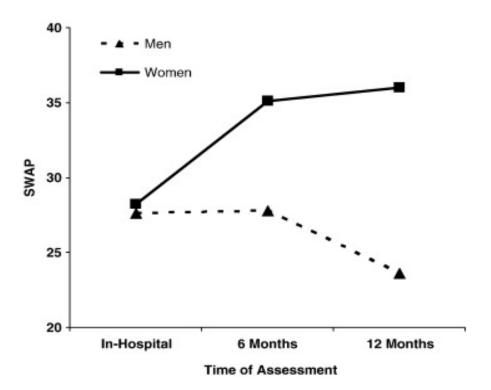


Figure 1. Satisfaction with appearance scores following burn injury for men and women. High SWAP scores represent low satisfaction ratings¹.

These are important findings but fail to explore why such a sex difference occurs. Examining women's stories regarding their interpretations and understandings of their body following burn injury is one way to explore the connection between the way they experience their bodies and their body esteem. Topics such as mental health, social interaction, and pain, all themes deemed pertinent to burn survivors in the literature and intimately connected to body image, will be explored with female burn survivors to help generate a deeper understanding of body image and its implications in burn rehabilitation.

Mental health.

As previously mentioned, body image dissatisfaction is closely tied to mental health outcomes following burn injury (Fauerbach et. al., 2002). Unfortunately, burn patients' emotional needs are often overshadowed due to major emphasis on survival and physical recovery (Wiechman & Patterson, 2004). Mental health is however a serious concern following burn injury with psychological outcomes including depression, anxiety, and, posttraumatic stress disorder (PTSD; Wiechman & Patterson, 2004). Mental health outcomes are particularly important problems to address in the burn population given the high premorbid psychopathology present in this population which often worsens after traumatic injury (Patterson, Everett, Bombardier, Ouestad, & Marvin, 1993).

Specifically, 22-45% of burn patients suffer from PTSD twelve months post injury, while many more experience subclinical levels (Selvaggi et al., 2005). Additionally, the association between depression and burn injury is strong with 20-30% of long-term burn survivors indicating depressive symptoms on a self-report survey (Lawrence et al., 2006a). Anxiety is also prevalent in this population with Wallace, Lees, and Bernstein (1987) reporting that approximately 26% of burn patients suffer from anxiety. Although these mental health problems are debilitating by

themselves, they are also responsible for the development of secondary problems. For example, Edwards et al. (2007) found that with burn injury, depressive symptoms were a significant predictor of increased pain and reductions of physical functioning, while anxiety predicted elevations in fatigue. Clearly, mental health is a significant problem in the burn population.

As previously mentioned, body image and mental health are strongly linked because body image dissatisfaction after burn injury is one of the most salient predictors of subsequent mental disorders. For example, Lawrence et al. (2006b) found that body esteem, social support, and social comfort account for approximately 60% of variance in depression for this population. More specifically, Thombs et al. (2007) found a substantial variance of depressive symptoms was explained by body image dissatisfaction in burn patients one year post injury. It is helpful to it emphasize here the major role body image dissatisfaction plays regarding psychological functioning. Considering burn injury has been shown to hinder psychological adjustment and subsequent quality of life, it is imperative to continue research in the area. Examining the subjective experience of burn injury patients, a richer understanding of the processes and implications burn injury has on mental health concerns will emerge.

It is particularly important to understand women's experiences concerning mental health and burn injury because research indicates that women have a unique experience when it comes to dealing with the psychological problems related to burn injury. Specifically, research has found females to be at greater risk for psychological distress including higher vulnerability to PTSD, general and social anxiety, and decreased body esteem following burn injury (Summer, Puntillo, Miaskowski, Green, & Levine, 2007; Thombs et al., 2007; Wiechman & Patterson, 2004). Although many studies have reported higher mental health risk for women following burn injury, researchers have failed to address the implications this has for women. For example,

although it may be 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 will reveal an important layer to the complex treatment of burn care, rehabilitation, and psychological interventions.

Pain.

Understandably, pain is a very significant issue with burn injuries. As patients progress through treatment and rehabilitation, they typically experience four different types of pain associated with the injury (Patterson, Tininenko, & Ptacek, 2006): procedural (pain cause by wound debridement, dressing changes, and physical and occupational therapy that requires manipulation of inflamed tissue), background (a persistent, mild to moderate pain which is present when the patient is immobile), breakthrough (pain associate with movement), and chronic pain (pain present long after the rehabilitation phase). Additionally troubling, burn pain can get worse over time (Summer, et. al., 2007), unlike pain from surgery or other traumatic injury which heals and ameliorates rapidly over time. Furthermore, pain often becomes chronic with 52% of burn patients reporting chronic pain twelve years after their injury (Summer et al., 2007). Given the complexity and intensity of burn pain, pain is cited as the primary concern burn patients have regarding their treatment (Summer et al., 2007; Tengvall, Bjornhagen, Lindholm, Jonsson, & Wengstrom, 2006). This concern appears to be largely overlooked however, as researchers continue to report that pain management is undertreated which contributes to future psychological distress including depression and anxiety (Edwards et al., 2007; Tengvall et al., 2006; Ullrich, Wiechman, & Patterson, 2009).

Pain is an important factor to consider when investigating burns and body image because pain understandably effects how one experiences his or her body; thus, pain may influence how one negotiates a new self-identity following burn injury. This point is emphasized in the book *Narrative, Pain, and Suffering*, which suggests that the way in which a person makes meaning of their pain, in relation to their life, will impact their health and wellness (Carr, Loeser, & Morris, 2005). Additionally, pain has been shown to impact the way in which people construct narratives and this influences how they come to understand their new self-identity (Sparkes & Smith, 2008). For example, a study investigating how people with persistent pain experience daily life found that their narratives were disjointed due to the interfering effects their pain was having on concentration and attention (Nilsen & Elstad, 2009). Similarly, Frank (1995) explains that people with chronic illness or injury may construct narratives that are chaotic and fragmented, making it difficult to reflect on their own experience. The stories burn survivors tell reveals how they negotiate their experience of pain, their body, and their identity.

Pain is specifically relevant for women because research has repeatedly shown that women perceive and experience pain differently than men (Hoffman, Garcia-Palacios, Kapa, Beecher, & Sharar, 2003; Keogh & Denford, 2009). Specifically, women, as compared to men, have a lower threshold and tolerance to experimentally induced pain (Bradbury, 2003), they report more pain, develop more chronic pain disorders, and tend to report more diffuse pain (as opposed to men who report pain in specific areas) which can lead to misdiagnosis. Interestingly, it has been suggested that both sex and gender influence the experience of pain (Bradbury, 2003); that is, sex may influence the experience of pain but gender role expectations often influence the expression of pain (McClelland & McCubbin, 2008). For example, women tend to report more pain when others are present whereas men report less pain in the presence of others.

Consequently, women may be more likely to communicate their reactions to pain, may be more comfortable expressing pain, and may be better able to seek out and receive social support, than men. Because it has been shown repeatedly that there is a marked sex (and gender) difference with the experience of pain, exploration of women's interpretation of pain will offer crucial information for understanding this issue.

This sex difference carries over into the burn literature regarding pain in that research indicates women are at greater risk for psychological problems following burn injury which may be increased by unaddressed pain management. For example, Ullrich, Wiechman, and Patterson (2009) found that with burns, the association between pain and physical functioning were greater for those patients with higher depression scores. If, as indicated above, women burn patients are at greater risk for depression, they will accordingly be at greater risk for higher pain and worse physical ability, resulting in poorer overall wellbeing following burn injury. Additionally, van Loey, Maas, Faber, and Taal (2003) found that sex was a contributing factor in the development of acute pain related to posttraumatic stress disorder, with women being at greater risk.

Social implications.

Aside from direct physical consequences of burn injury, patients must also begin to navigate social situations again, with a different body and self-concept. Jack (1991) explains, "[a] person's body carries social meanings that profoundly affect the sense of self. We come to relation with people through a body whose sex, size, and shape, elicit responses from others that enhance or diminish our feelings or confidence, self-esteem, and safety" (p. 15). Social interaction often proves difficult for burn survivors as research has shown that visibly disfigured populations are victims of a social process that defines them as deviant and consequently they are recipients of dehumanizing behaviours such as bullying or staring which may have life-long

effects on body image, self-esteem, sexual satisfaction, and quality of life (Fauerbach et al., 2002; Lawrence, Fauerbach, Heinberg, et al., 2006). Social devaluation processes exists in different social situations; social stressors faced by many burn survivors include family strain, sexual issues, return to work, and interaction with strangers in daily life (Wiechman & Patterson, 2004). Additionally, psychological literature shows several illustrations of devaluations, avoidance, and rejection of people with non-typical attributes (Kent, 2002). As a result, these attributes can decrease quality of life in that people with disfiguring conditions are more likely to report avoidance of social situations, high levels of distress (particularity anxiety), poorer sexual satisfaction, and low levels of self-confidence (Fauerbach, et al., 2002; Kent, 2002).

Sexuality may be considered as one of the most intimate forms of social interaction. As alluded to previously, sexuality is frequently cited as a major area of concern regarding social interaction following burn injury (Andersen & LeGrand, 1991; Bitzer, Platano, Tschudin, & Alder, 2007). Sexuality is an important factor to discuss specifically in terms of body image dissatisfaction and burn injury because body image attitudes are correlated with interest in engaging in sexual activity (Andersen & LeGrand, 1991), thus suggesting that when body image is disrupted it may in turn affect sexuality. One study looking at adults burned as children revealed that sexual experiences were somewhat negative for burn survivors, evident in their disclosure about covering scars and negative self-talk during romantic encounters (Forbes-Duchart, McMillan-Law, & Nicholson, 2006). Although there is little research on sexuality and burn injury, research focusing on medical illness offers some insightful studies that presumably generalize to burn injury. Disease has been shown to affect sexuality through decreased mobility, chronic pain, and visible changes to the body caused by illness. Considering burn injury results in similar symptoms (decreased mobility, chronic pain, and changes to one's body), these

findings may carry over to burn injury. Bitzer et al. (2007) investigated the importance of sexuality in the context of disease and found that chronic medical conditions are frequently associated with sexual difficulties, but are often underreported and underdiagnosed.

Social interaction difficulties may be particularly pronounced for women following burn injury because women have long been thought of as the 'more social gender' and are also found to suffer from social anxiety and social phobia more often than men (Antony & Stein, 2009), suggesting that women may experience great social difficulties following burn injury. Jack (1991) explains that, "a women's body operates as a trigger for certain types of social interactions that are integrated into her sense of self-in-relation" (p. 5). Significant change to one's body and concept of the self will presumably modify social interaction because social interaction requires the presentation, including physical aspects, of the self to others. Additionally, sexuality following burn injury may be particularity pertinent to women because studies suggest that permanent alterations in physical appearance predict poorer sexual satisfaction and poorer self-esteem in women, but not men (Fauerbach et al., 2002). Furthermore, it has been shown that burn patients, especially women, often suffer from sexual dysfunction as well as a decrease in sexual satisfaction (Selvaggi et al., 2005; Wiechman & Patterson, 2004). Farvid and Braun (2006) found that female sexuality was linked to physical appearance and concluded there is criteria for 'attractive' and 'appropriate' femininity based on certain levels of sexuality. Accordingly, internal conceptions and external expression of sexuality are important; not only for sexuality in terms of the act of sex but also the emotional, cognitive, and behavioural experience of a sexual nature.

There is, however, a missing link in the literature on social interaction and non-normative appearance which is the patients' perspectives. Although research has identified the important

social processes and consequences of such conditions, it has failed to address how the people with non-normative appearance come to understand their new bodies and the social processes that are presumably affecting them. Although it may be true that stigmatisation leads to the development of appearance anxiety for those with non-typical appearance, it fails to capture the complete picture. Thus, exploring the patients' perspectives would contribute additional complexity to the understanding of burn injury. Specifically, exploring how women conceptualize their sexuality and to what degree they relate it to physical attributes will facilitate a better understanding of how burn injury impacts women. Similarly, how women have negotiated their new sense of self in relation to their changed body may impact their social behaviour and interpretations of social interaction. Given the psychological benefits of social interaction, it is imperative to explore how the experience of one's body following burn injury changes their social experience.

Current Study

Despite the vast amounts of research which has been done on burn injury, two major deficits remain in the literature. Firstly, current trends in research avoid taking gender into account, often to avoid stereotypical assumptions, with most research being conducted in a gender-neutral way. It is important to take gender into consideration in burn research however because of the vital role gender plays in the factors relating to traumatic injury such as body image dissatisfaction and mental health (Thombs et al., 2007). Secondly, the current burn literature is primarily focused on quantitative aspects of burn injury. Researchers have devoted considerable efforts to measuring mental health, pain, and body image satisfaction following burn injuries but have failed to explore what burn injury means to the individual. Although it is useful to measure these aspects of burn injury objectively, it is also critical to understand how

burn patients interpret, understand, and make sense of their injury through examining their stories. An important dimension of burn injury is revealed when the patients share how they perceive, interpret, and cope with their injury.

This study addresses these shortcomings with the use of narrative-discursive analysis to examine women's stories about their burn injury. The current literature, discussed above, provides a good starting point for understanding burn injury but fails to provide insight into what the injury means to the patient; that is, there is little information on their stories and on how they understand and give meaning to the unexpected traumatic event and its consequences. Examining how women interpret and understand their injury and its consequences, through narrative research, will allow for a richer understanding of burn injury. This point is well exemplified by Frank (1995) when he notes that illness narratives "give voice to an experience that medicine cannot describe" (p. 18). Through talking about pain, mental health, and social interaction women's narratives about their burn injury and its relation to body image are revealed.

Narrative is appropriate for this study because it is through narrative that people try to explain and make sense of their experience. Budgeon (2003) explains that "telling stories about the self is a useful strategy for opening up the concept of identity to investigation" (p. 51) which will prove particularly useful in this investigation of how women experience their bodies after burn injury. Although experimental and quantitative research designs have contributed significantly to the study of women in psychology and other fields, many researchers have come to believe that the problems associated with quantitative methods can be best addressed and solved through the use of qualitative research (Landrine, Klonoff, & Brown-Collins, 1992; Paludi, 2004). Specifically, exploring patients' narratives emphasizes their perspective on the

topic at hand and may contribute to a greater, deeper understanding of pertinent issues following burn injury. This study compares the participant's narratives with the greater cultural narrative in order to better understand the burn injury experience. Generally, the intent was to make sense of the meanings others make about their burn injury, their identity, and their life situation.

The broad framework of this study is social constructivism, which posits that subjective meanings are negotiated socially and historically and "emphasizes diverse local worlds, multiple realities, and complexities of particular worlds, views, and actions" (Creswell, 2007, p. 65). Broad open ended questions used in this study were employed so that participants could form meaning of a situation and construct comprehensive narratives in response.

Methods

Ethical Considerations

Ethical guidelines and procedures outlined by the University of Manitoba were strictly followed. Ethical approval was granted by the Health Research Ethics Board of the University of Manitoba. The researchers involved in this project had all completed training in how to conduct research confidentially in accordance with regional guidelines. No difficulties with the participants were encountered in the course of the study. Prior research indicates that a majority of burn patients accept research participation and even find it beneficial (Willebrand, Wikehult, & Ekselius, 2004). Furthermore, it has been shown that talking about traumatic events does not increase the chance of acquiring or worsening psychological symptoms and often improves wellbeing (Niederhoffer & Pennebaker, 2009). In case psychological difficulty did arise with a participant, procedures were in place to ensure that participant received appropriate psychological attention.

Participants

Eight female burn survivors were interviewed for this study. The women had between 1-and 18% total body surface area (TBSA) burns to various parts of their bodies. Women with 30% TBSA burns, or greater, were excluded from the study as it has been shown that burns over 30% have distinctive psychological outcomes (Noronha & Faust, 2007). Half of the participants had hand burns while others suffered burns to their legs, chests, arms, or face. Length of hospital stay varied between participants and ranged between several hours to three months. Recruitment was ongoing until saturation in the data was met which was anticipated to be approximately 10 women but was met after eight interviews. Following the transcription of five interviews, it appeared that no new narrative data was being collected however three more interviews were collected to ensure saturation of data was met. Participants ranged in age from 18 to 72 (average age=41) and were all able to proficiently communicate verbally in English. None had any signs of cognitive impairment.

Bio-sketches.

In order to give the reader context brief bio-sketches are provided below based on field-notes collected during and immediately following each interview. Given the complexity of narratives and considering the different characteristics that influence the narratives used in this research, it is important to understand the sample from which these narratives have been collected. Providing the bio-sketches allow the reader to more fully understand the experience of the participants and grasp the important discourse developed in this paper. Names and identifying information has been changed in order to protect participants' confidentiality and specific demographics are not provided (e.g. specific age).

Eva.

Eva is a married white woman in her sixties, living in a suburban neighbourhood. She has a university degree and although her retirement was planned before her burn injury, Eva never returned to work as a communications and marketing specialist after her injury. Eva's nightgown caught fire on a stove and burned her upper arm resulting in a 3% TBSA burn.

Eva was the first participant in this study. I had met her months prior to the interviews as I was observing procedures conducted at a burn clinic. At that time, Eva seemed more distraught regarding her burn than other patients I observed that day. She appeared quite vocal about the difficulties she was having which left her appearing despondent about the situation.

During the interview, Eva was very talkative and open with sharing her experience. She was willing to talk about her injury and the associated feelings and was also willing to show her scar to the investigator without hesitation. Eva was thoughtful about answering questions and revealed that she had thought of some of these issues previously. Although Eva laughed a lot during the interview, which appeared to be a nervous, self-conscious laugh, she seemed willing to talking about sensitive subjects. Eva seemed to enjoy being able to talk about her experience and appreciated someone listening to her story. Good rapport developed quickly between Eva and the interviewer which presumably encouraged Eva to be more comfortable and open in the interview.

Tracy.

Tracy is a divorced, white, woman in her forties. She has completed high school and some college courses and currently works at a bank. Tracy was burned while preparing dinner in her suburban trailer home when a pot of hot oil caught fire. Tracy grabbed the burning pot to bring it outside which resulted in a 1% burn to her right hand. She was required to take one month off

work following the injury to recover from the burn as well as a skin graft operation due to the burn.

Tracy was very talkative throughout the interview and was able to quickly develop rapport with the interviewer. Although talkative, she revealed little about how the burn affected her sense of self, her self-esteem, or her life in general. Tracy seemed to have a bit of trouble staying on topic and would often speak about topics that were not introduced by the interviewer for long segments. For example, Tracy spoke in depth about the stigma surrounding mental illness and the struggles experienced by her sons.

Liz.

Liz is a white university student in her twenties. Liz was burned (9% TBSA) on her left foot and leg in a hot tub malfunction in 2009. At the time of the interview, Liz was attending university and was working part-time in her field of study. She had been off work for 4 weeks and was planning on returning shortly as her financial situation was worrying her. She felt well supported by her family emotionally, physically, and in terms of having the opportunity to live at her family's suburban home.

She was an eager participant as she agreed to meet on a different day at a different location. The interview was conducted at the university as this location was mutually convenient for the participant and interviewer. Liz seemed comfortable from the onset of the interview as she was talkative, confident, and in good spirits. Liz and the interviewer developed good rapport quickly as they had much in common through age, education, and life experiences.

Sara.

Sara is a recently married woman in her late twenties who self-identified as a Chinese Canadian living close to an urban center. She was recruited during a follow up burn appointment.

Her husband had accompanied her and they had wished to participate in the interview together, however, Sara was advised by the interviewer to participate individually and she agreed. She did however come across as quite shy and nervous initially, which may have been eased had her husband been present. Sara laughed nervously through-out the interview although better rapport was slowly developed as she became more comfortable with the setting and the interviewer.

Sara was recovering from a 1.5% TBSA burn to her arms, chest, and right leg, sustained by a hot oil cooking accident. At the time of the interview Sara had been off work as a health care professional for approximately 2 weeks and had planned to return to work shortly. Sara's interview was unique because, due to other health reasons, she was unable to take prescribed pain medications for her injury. Sara seemed to be the most concerned about her changed physical appearance although she was not the most severely injured. Sara laughed nervously throughout the interview however she seemed to become more comfortable as the interview progressed and shared more personal details about herself and her experience.

Sue.

Sue is a retired, white, health care worker in her seventies who is married with grown children. Sue was very blunt and straight-forward in the interview which was emphasized by her stern accent. Sue seemed to open up quickly to the interviewer. She expressed her comfort with the interviewer at the end of the session and even gave the interviewer a hug. Sue was comfortable talking about many aspects of her injury and was willing to show her burn, exposing her chest and severe scarring to the interviewer. Additionally, Sue brought up sexuality on her own which is rare considering most participants were unwilling to discuss this topic at all.

Sue was the most severely burned participant in this study with a 18% TBSA burn to her right arm, both hands, and chest. She was hospitalized for just over 1 month following her injury

which was the result of a cooking accident in her suburban home. As Sue was retired, she had no plans on returning to work. At the time of the interview, Sue wanted further surgery to fix her hands, continued to deal with itchiness and pain, and believed she was still in the recovery phase, approximately 1 year post-injury.

Carrie.

Carrie was the youngest participant in this study at the age of eighteen and had recently moved from Southeast Asia with her family. She seemed young for an eighteen year old, still living in her family's suburban home and not working or in school. Carrie was soft spoken and had a slight accent. It seemed as though she, at times, had difficulty expressing what she really wished to say due to a language barrier. Despite this language barrier, which may have influenced the richness of the interview, her narratives were still very informative. Carrie's interview was conducted in her family home, in her bedroom, which she chose because this is where she felt the most comfortable. Regardless of this comfort, Carrie appeared very shy and rarely expanded her narratives beyond basic answers.

Carrie suffered 2% TBSA burns to her left foot and right arm in 2010. Carrie's burn was a result of a kitchen fire on the stove. As the house filled with smoke, Carrie realized the pan she was using to heat oil was on fire and tried to save the kitchen by removing the pan from the house, which in turn caused her burn. She was treated in emergency care and returned home the same day. At the time of the interview, Carrie was still on crutches from the burn but expressed little disruption to her life as she rarely left her house prior to the injury.

Lori.

Lori is in her late twenties and was living on a First Nation's reservation at the time of her injury. Lori sustained a 5% TBSA burn to her face but the details of how the injury happened

were inconsistent. Lori explained that she was intoxicated at the time of injury when she was pushed into a bon fire at a friend's house after an altercation with a group of women. Her chart revealed however that it was a result of domestic abuse. At the time of the interview Lori was living in public housing provided to patients who live outside of the city. She had been employed as a home care worker where she lived but was fired prior to her injury. Lori wished to return to that job upon returning home after recovery.

Lori was very quiet and timid. She rarely made eye-contact with the interviewer and looked in the opposite direction during the brief recruitment session. This may have been a result of cultural differences or due to the fact that Lori suffered facial burns and was feeling self-conscious about the injury. Lori seemed to adjust quickly to the interview situation and was willing to share openly. Lori was the most emotional participant and cried when recounting the circumstances of her injury. While Lori seemed hesitant about participating initially, rapport developed between her and the interviewer and by the end, Lori seemed to want to continue the interview; it seemed as though she enjoyed being listened to.

Holly.

Holly is a white receptionist in her fifties who is married with grown children. She lives in a rural community with her husband. Holly sustained a 1% TBSA burn to her right hand as a result of a cooking accident in late 2009. She was treated in emergency care and returned home the same day, and to work the following day.

Holly was outgoing and friendly. She was open about talking about her injury but seemed unaffected by her injury and thus was not sharing very intimate details about herself. Interestingly, although she presented as well-adjusted to her injury, revealing very little struggle, she broke into tears nearing the end of the interview when asked what she would tell someone

else who suffered a burn injury. Holly explained that this surprised her as she had thought she had "dealt" with her injury, but that this experience gave her new things to consider.

Recruitment

A purposeful sample of eight female burn survivors was recruited from the follow-up burn clinic at a major downtown hospital in a medium sized Canadian city. A health care professional identified patients who met inclusion criteria and asked if they could be approached for research recruitment. Those who agreed were approached by the researcher at which time she explained the study in more detail to ensure the patient understood that involvement in the study would not be connected with her treatment and would not interfere or affect treatment in any way. The ethical protocol was explained and the participant was given a hard copy. After written consent was given, the interview was arranged and in most cases proceeded directly following the patient's visit at the clinic. In cases where same day interviews were not feasible, alternate appointments were arranged for the interview to be conducted at a time and place convenient for both the participant and interviewer. Consent was also confirmed at the onset of the interview (see Appendix A).

Data Collection Procedure

Following informed consent, as described above, in-depth semi-structured interviews were conducted. Interviews, lasting an hour, were tape-recorded and field notes were taken during and after the interview to record interview environment, participant reactions and presentation, and any non-verbal communication. Additional medical information, such as size, location, and severity of burn, was collected from the participants' medical charts.

Following the interview, tape-recordings of the interview were transcribed verbatim by the researcher using the transcription conventions outlined in Appendix B. The immediate

transcription and coding of interviews allowed the researcher to gauge when theoretical saturation was met, or in other words, when no new information appeared to be collected, at which point data collection was terminated. Transcriptions and digital recordings were stored in password protected documents saved on a laboratory computer. Pseudonyms were assigned to each participant and any identifying information was changed to ensure anonymity.

Instruments

An in-depth semi-structured interview schedule, developed by the researcher, was followed to conduct the participant interviews (see Appendix C & D). The interview process was developed to be emergent and thus although questions were outlined, the interviews followed the natural flow of conversation allowing for questions to be added and deleted as deemed necessary by the interviewer during the course of each individual interview. However, the interviewer ensured that all main topics were covered in each interview. The general order of the questions remained consistent in order to ensure that personal and more emotional questions were asked after the participants were comfortable with the interview situation, topics, and interviewer herself. Additionally, a demographic sheet (see Appendix C) including information such as age, occupation, cultural background, and injury data, was used to collect pertinent information both during the interview and from the participant's medical chart.

Data Analysis

Following interview transcription, narratives were analyzed using a narrative-discourse method. Each individual interview transcript was read and meaningful segments were coded and subsequently analyzed using thematic, structural, and performative approaches looking at both unique and general characteristics of the narratives. Additionally, the relation the participant has to others, as well as the relation specifically to the researcher, was considered and explored. 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. Subsequently, the larger meaning of the combined narratives was interpreted and represented by focusing on themes, content, and structure. Analytical bracketing was employed to facilitate shifting between different narrative realities in order to accomplish a complete analysis of the transcripts. Although thematic, structural, and performative analysis methods are discussed separately, it is important to note that they may often overlap and in doing so complement each other.

Thematic analysis.

The focus of the thematic analysis was to examine *what* is 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 then 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 along with interpretations by the researchers, theoretical viewpoints, and past research to develop an advanced understanding of a phenomenon rather than an explanation. Particular attention was paid to delineating dominant narratives from those narratives that appeared less developed, called subordinate narratives.

Structural analysis.

Structural analysis went beyond examining *what* is being said and focused on *the way* in which it was being said on both a macro level (examining plotlines of the narratives) and on a micro level (examining the narratives on a elemental level exploring the temporal and spacial organization). Thus, the way in which the participant used language to narrate and organize their

story was examined. Each interview was examined based on narrative-discursive analytical method which involved examining the structure and language of the transcript, and furthermore examining more detailed narrative forms, stylistic features, and discursive strategies in the narratives. This method was used to code for the inner organization of the narratives such as chaotic, associative, or fragmented status (Frank, 1995). The five levels of structural analysis outlined by Emerson and Frosh (2009) were followed. This included (1) examining the organization of the text overall, (2) examining the syntax and cohesion, which involved exploring why the speaker makes certain connections and whether they make sense within the context of the interview, (3) looking at what the main point of the plot is, (4) interpreting the psychological subject of a particular section to question why the speaker changes subjects or viewpoints, and (5) examining the focusing system and asking why a certain focus is important based on how it was said. Specifically, sequences and structural parts of the narrative that reoccur were indentified in order to determine the function of a particular segment. This approach allowed for interpretation of multiple narratives such as dominant, subordinate, cultural, and counter narratives.

Performative analysis.

The focus of performative analysis is to examine *why* certain narratives are being expressed. According to Riessman (2008) performative analysis examines narratives in terms of relation and interactivity and regards narratives as a performance. That is, questioning who the audience is, who the narrative is directed at, and why it is being told. Performative analysis is also concerned with contexts, such as the interview setting, the researcher's influence, and of particular importance in this study, cultural influences. For instance, this study compared the cultural narrative regarding burn injury and body image to narratives that were presented by burn

survivors themselves and examined how they counter cultural ideals or devaluations. Therefore, this method of analysis emphasizes the position the narrator is taking and what the purpose of the story is.

Validity.

In order to establish validity, or trustworthiness, in this study, Lincoln and Guba's (1985) criteria were considered which included credibility, transferability, dependability, and confirmability. Credibility deals with the accuracy to which the researcher has described the human experience (Sandelowski, 1986). To help ensure credibility, persistent observation, memoing, transcript editing, integration of field notes, and continuous validation with the use of reflective listening was employed (Woodgate, 1993). Furthermore, triangulation was employed through the integration of field notes, medical charts, and demographic information into the analysis and results. To ensure transferability (Lincoln & Buba, 1985), or the extent to which the findings apply to other situations, theoretical sampling and descriptively thick and rich data was used and detailed information was provided in the communication of results so that readers can identify similar situations in similar contexts (Woodgate, 1993). Dependability is concerned with consistency and was ensured by providing a detailed description of the study including methodology and analysis allowing other researchers to duplicate the study and presumably come to similar conclusions. Additionally, dependability was ensured by selecting participants who were interested and have knowledge of and experience with the research topic and having only one researcher collect the data. Confirmability addresses concerns regarding researcher biases and was addressed through neutrality which was enhanced by reducing distance between the researcher and participant through empathic listening techniques (Lincoln & Guba, 1985), by

documenting the researcher's assumptions and perceptions, and by having other researchers familiar with the material review the analysis and results, thus ensuring consensual validity.

Results

"Doing well": The dominant narrative

The interview questions in this study emerged from the current burn literature and covered areas identified as key in burn recovery such as pain, body image, sexuality, social interaction, and mental health. In discussing these areas, the women presented an overriding theme of 'doing well' in all aspects of recovery. The dominant narrative presented by the women in this study seems to resist the cultural narrative regarding burn survivors as sufferers. The women predominantly presented themselves as strong and fully recovered with few emotional difficulties; this is counter to the cultural narrative which would suggest that they are weak, maladjusted, or victims of their injury. The narratives about body image, pain, mental health, sexuality, and social interaction all predominantly depicted healthy, happy, women who had very little negativity regarding their burn injury. More subtle aspects of their narratives, which will be explored later, however presented a subordinate narrative with different implications. Although some women acknowledged some areas of difficulty, they emphasized that the burn injury had not changed their life in a significant way. To follow, examples of how the women in this study resisted the cultural narrative, within each pertinent area, will be discussed.

Tracy's narrative to follow exemplifies the overall attitude the women portrayed regarding their burn injury. That is, they present a positive outlook on the injury with little affecting the way in which they live or conceptualize their lives, as if their burn injury is not something to be concerned with.

I: Is there anything that I haven't asked you that you think is important?

Tracy: (1) well (2) I don't know (1) um (2) let's see. (1) See a lot of people (1) think (1) that it should affect me different. Or how I should see myself. But it doesn't. You know, itit doesn't matter to me that I burnt myself. It doesn't matter that I have to wear this. It doesn't matter that when I don't wear this, it's still going to be a big scar. It doesn't change how I see myself. It doesn't change how I feel about myself. It doesn't change how the people that matter to me, see me, you know. That's-what a stranger thinks of me, I don't care. I really just don't give a damn what they think. It's not their problem; they don't have to live with it. It's mine. I don't find it a problem. It hasn't changed how I feel about myself.

This narrative is a useful example in depicting how many of the women seemed to appear clearly unaffected by their injury. Tracy seems to be aware of the cultural narrative about burn survivors in that she felt as though people were expecting her to be "affected differently". Her response to this feeling emphasizes that her injury did not change anything about her, or how she feels about herself. This type of narrative is exemplified through various dominant narratives about pain, social interaction, and body image.

Selvaggi et al. (2005) found that most burn survivors, regardless of burn severity, experience body image concerns as they are left with non-typical appearances even after reconstructive surgeries (Lawrence, Fauerbach, Heinberg, et al. 2006). In contrast, the women in this study appear unconcerned about the way their body looks or their scarring. Holly, for example, seems not to be concerned with her appearance following a 1% burn to her hand (a highly visible injury) in the following segment.

I: Are you expecting permanent scarring?

Holly: Oh, I'm sure there will be some. But I'm not worrying about that. I can still use my hand

I: So you're not so concerned about the appearance more functionality?

Holly: Uhhum, that's right.

Sue, who suffered the highest TBSA in this study with burns to her chest, arms, and hands, shared a similar unconcerned and short narrative regarding her changed body.

I: Has it changed the way you feel about your body?

Sue: No. No, uh-uhn, not at all.

Additionally, in their stories about body image, women expressed no hesitation about showing

others their scars and many participants offered to show the interviewer their scars, indicating the

comfort they felt with their bodies. Several women explained they were not concerned about

showing people their scarring, as exemplified in the following excerpts.

Eva: I'm not afraid to show my arm, you know, if people want to see it.

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Tracy: Oh yea, I had no hesitation about showing people at work what it looks like. Even though they're going like, 'oh no, no, no, no, no' ((laughs)). They're going, 'ew, ew, ew, no, no, no' before they've even seen it because they saw it in the beginning. They're thinking it's really gross looking. You know? So.

I: How do you think it looks?

Tracy: I think it looks fine.

~~~

Liz: I never was embarrassed. It was more so like, 'check it out', 'look at this', ok. Check this out. Like this one, this is what I had to do through.

Sue and Holly were abrupt in answering questions about their changed bodies and did not offer detailed or rich narratives regarding this topic. Furthermore, Eva and Liz's statements are perplexing given that later in their interviews they questioned what type of clothing they would wear to ensure their scars were covered. The shortness and ambiguity with this topic was typical of narratives from the women and leaves the reader expecting more.

The women continued to appear unaffected by their injury in their narratives about pain. Pain is a major topic in burn research and is often cited as the primary concern for burn survivors following burn injury (Summer et al., 2007). A strikingly different dominant narrative emerged with many women explaining that the pain from their burn was not significant. Although this discrepancy is hard to explain considering the research in the area is not well understood, it is not surprising given the complex nature of pain. To follow, Eva explains that the pain experienced from her burn was not even close the some other pain she has suffered in her life.

Eva: Well you know, it was very strange kind of pain. [I: Oh yeah?] Um, and I've had, you know I've had four children so I've had (4) [I: You know pain] I know pain. I've had a gallbladder removed, I had gallbladder attack, I had- that is <u>real</u> pain. I've had a toothache where you want somebody to shoot you. Had that kind of pain. [I: yeah]. This kind of pain, it hurt, but I-I could sort of cope with it. But it was sort of like it was strange feeling. Ah, which made it kind of different and even when I took like these heavy duty drugs, it never, it never really went away. This-this kinda strange feeling and in fact I can remember being a teenager and you know having cramps you-you know you just wanna, yeah, once again somebody to shoot you [I: Yeah, yeah]. And taking like a 222 and like within like five minutes it just, all just melts away. Well this, I had some pretty heavy duty medication, and it reduced it, it softened it, but it never really went away.

Although Eva does acknowledge having pain, she describes it as strange and different rather than extreme, excruciating, or breathtaking. In fact, she suggests that it's not even *real* pain, as if it were not worth mentioning. Similarly, Tracy and Liz state experiencing no pain at all in the following experts.

I: Where you in any pain with your hand?

Tracy: Not really.

I: No?

Tracy: No.

I: Wow. Discomfort or?

Tracy: It feels like, you know how like ah, ah when your leg goes to sleep. [I: Um-hum. Like prickly, or?] Nope, not prickly but numb.

~~~

I: And what kind of pain are you in now, if any?

Liz: Um, I'm not (1) in much at all. Um(:) it's more of just like a discomfort not like necessarily like a pain. Like I'm off, ah, my pain meds and I'm just taking Advil every so often.

Similarly, when asked about her current pain, Eva states, "I won't describe it as pain; I would describe it as discomfort, yes". Pain, both at the time of the injury and during rehabilitation, is minimized by these narratives and does not appear to be a dominant concern for these women following burn injury.

Mental health following traumatic burn injury is a concern with posttraumatic stress disorder, anxiety, and, depression being prevalent in the population and was thus one of the interview topics. The women interviewed in this study did not appear to suffer from

psychological difficulties related to their injuries. When questioned about how they were coming to terms with their injury, the women did not seem to have very layered narratives. Eva, for example, responds in one sentence, "[o]h I'm-I-I'm managing fine". Even when probed by the interviewer to expand, Eva was resistant to talk about any psychological issues or emotional difficulties. Liz also presented a common response, below, to another mental health question and portrayed continuity of self following traumatic injury.

I: How do you think your mood has changed at all kind of over this process? Liz: Um no. I still, I still have the same humour and same outlook on life I'm not suddenly bitter, or you know angry, for no reason, so.

When question about how they were managing with their injury or how they came to terms with the injury, most women explained it was just something to deal with, as if it was not a big problem but rather simply another annoyance in their life.

Tracy: Yeah. It's just something do deal with, you know ((laughs)). Deal with now, get on with the next thing.

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Sue: Well, because I'm a positive person, I think (2). It's my problem and the problems that I have are mine. And it happened and what does it help ... I'm not a complainer. I-you know, I'm a demander.

~~~

Holly: You know what; I'm not that kind of person that will let little things like that bug me. Ah (1) if, I mean life happens so you just move on with it, right. I know that some people would have a difficult time with it, but I've never been like that. Maybe it's just my personality

Contrary to many research finding on burn survivors, most women in this study appeared to be well adjusted to their injury and did not report any mental health problems. Although some women were willing to discuss the 'hardest part of the experience', it was only after probing by the interviewer that the women shared any hardship. They were primarily concerned with presenting positive narratives or recovery, with little psychological turmoil.

Although disfiguring injuries are known to cause social discomfort and problems in intimate relationships, again, the women seemed to present an opposing narrative. Holly presents an exemplary narrative regarding how they feel in social situations and even puts the onus on others in the interaction.

I: So if somebody kind of pulls away when they shake your hand, what –

Holly: I just let them go and I just keep talking as if nothing happened. 'Cause if they're uncomfortable with it, it doesn't mean I have to be. So it just-just leave it.

I: So it's more like their-

Holly: It's their issue. It's not my issue because I've already dealt with it. So I-I don't, I don't worry about it.

Carrie also explains that she is not bothered by showing people her injury in the following response to a question regarding social interaction.

I: Yeah, how does that feel?

Carrie: I'm OK

I: Oh, you're OK with showing other people?

Carrie: Yeah

I: So it doesn't really-you don't feel like you have to hide it?

Carrie: No, 'cause if I hide it, they can still see the part of my foot, so.

The women were also asked about more personal social interaction such as how intimate relationships may have changed. Although sexuality was not discussed in all of the interviews, when it was, the women did not express any negative changes to that aspect of their lives. Holly's short and blunt narrative segment about her intimate relations with her husband to follow exemplifies the dismissive attitude the women shared regarding sexuality.

I: Do you think it affected your intimate relationship with your husband?

Holly: Nope.

I: Not at all?

Holly: Nope.

I: Did it change, either for the good or bad, your general relationship with your husband?

Holly: ((Shakes head, no))

Sue also explained on two separate parts of her interview that her husband still made sexual comments to her and was 'turned on' by her scarred, naked body. These women seemed

confident yet blunt and combative when asked about their social interactions. They seemed unwilling to discuss in any depth their changed appearance but rather placed the blame on others in interactions if they were uncomfortable with the scarring.

The final example of the women presenting "doing well" narratives is presented below in an interesting remark made by Tracy regarding the use of the term 'survivor' to refer to those who have experienced burn injuries.

### I: Do you feel like a burn survivor?

Tracy: No. No actually I don't ((laughs)). Because (2) I think a burn survivor is somebody who was burnt so badly that (1) it has affected their quality of life. This has not affected my quality of life. Um (1) like, (2) like people who (1) are burnt like, you know, and they just have like a patch of skin across here that <u>isn't</u> burnt, you know. Those people are burn survivors, if they live. And, like you see in pictures of them, like their faces just melted. Those are burn survivors. And that affects their quality or life. This doesn't affect my quality of life. I can earn my living. I'm not on disability. I'm doing the same job I was before, you know. So, it does not affect my life in a negative way, so.

Tracy explains that her injury is not 'bad enough' for her to be a burn survivor. Many women commented that others are much worse off than them which seemed to detract from their story or suffering. In the above excerpt, Tracy seems to feel as though the term 'survivor' perpetuates the idea that burn survivors are suffering and defective and does not wish to be viewed in that way, and thus she distances herself from it.

The above examples represent the women's dominant narrative of 'doing well'. One way to understand this is that the women seem to be resisting the cultural narrative with their own dominant narrative which directly opposes the cultural norm. Through emphasizing their positive adjustment to burn injury in their dominant narratives, the women are demonstrating their strength and are exerting control over how women burn survivors are typically perceived. They are not presenting the cultural narrative that they are weak and suffering due to a burn injury, which may further devalue their place in society, but rather they are presenting a counter

narrative which portrays them as unaffected, unchanged, and well-adjusted to their traumatic injury, that is, they are countering the cultural narrative.

# "Freddy Krueger": The subordinate narrative

The dominant narratives presented above seem perplexing given the extensive literature on burn recovery that suggests the opposite. The cultural narrative, along with psychological literature, portrays burn survivors as sufferers of traumatic psychological and physical injury. The contradictive evidence found in this study required further analysis to uncover a subordinate narrative to help understand the complex experience these women were facing. Their subordinate narratives seem to suggest that they do have stories of hardship, psychological turmoil, and physical struggle, but that these stories are being less emphasized or withheld. For example, Tracy, whose narrative appeared at the beginning of this paper, seemed confident and unaffected by her injury ("I think it looks fine"). However, her subordinate narrative reveals subtle indicators that she does view her body differently and non-typical. For instance, on numerous occasions she refers to her expectation that eventually her scarring will "look just like a regular" scar" and that her current treatment "makes it look normal". Subordinate narratives were revealed within discussion of body image, pain, mental health and social interactions, all suggesting that although the women emphasize the dominant, 'doing well' narrative, they do experience unpleasant incidents, thoughts, and feelings about these pertinent issues.

The subordinate narrative regarding body image emerged with the women being predominantly concerned about other's possible misappraisal that the scarring is a skin disease. Sara, to follow, is looking forward to having to return to work and expresses her concern about her appearance.

Sara: ...I don't know what they'll think; that I have a skin disorder or something ((laughing)). So that's all. I'm worried about that.

I: OK. Yeah. How do you think you'll deal with that?

Sara: Um well I'm going to try and probably hide it. Just so-just so then I don't get you know, weird reactions or whatever.

Liz shared a similar concern when she talked about her first time in public after her injury:

Liz: So I went into the store and that was the first time that I like felt self conscious about it. It's because now it was open to people I didn't know. As appose to my friends where I was like, you know, more of a joking side and they knew the story. Whereas now, you know, I was walking through Shopper's Drug Mart and people looking at me like I have a skin disease. Like a contagious skin disease.

Additionally, many women spoke about concerns about what they would wear, particularly concerning what clothing would best cover their scarring. A selection of comments from various participants about clothing selection follows.

Eva: So I don't know. Much-and I tend to wear long-sleeves anyhow. Um, although if it's hot summer day you want to wear (2) short-sleeves but I think that I wouldn't...I was thinking, would I wear a bathing suit? Hmm, no.

~~~

Liz: Or, like being a girl, I think about like what's it going to look like when I wear heals, you know, or nice shoes. Like people will look at nice shoes and then they're going to see my <u>foot.</u>

~~~

Sara: And I wanted to wear sometimes like the shorter cute summer dresses but now I have to go for the longer ones (1) 'cause I have some scars on the legs too ((laughing)). But yeah, otherwise as long as I could cover up I feel a bit better because I'm like, even if it's going to be really hot outside but I rather not show my scars.

The dominant body image narratives suggested that the women felt as though their injury did not affect the way they view or feel about their bodies. The above examples however reveal that they feel the need to cover up parts of their body to avoid exposing their scars to others, suggesting that they are not entirely comfortable with their changed bodies.

Opposing attitudes also emerged in subtle ways in the women's narratives through the use of metaphors and certain word use when they described their appearance. The most striking descriptions of the body came from participants who used metaphors to describe their burn injury. Two participants used popular culture references when describing their appearance. For

example, Lori, who suffered a 5% TBSA burn to her face, compares her appearance to that of popular culture's Freddy Krueger; a fictional serial killer recognized by his burnt and disfigured face. Another participant, Liz, also uses a popular culture reference when she compares her leg to blue science fiction creatures from the film Avatar, "[a]nd so ((laughing)) I have this like, destroyed foot looking thing and you can see all my blue veins and when my foot is down, all the blood rushes to it and it literally turns blue. Like I joke that I'm part Avatar now, because it's like literally <u>blue</u>".

Another common metaphor used to describe the body after burns was that of meat. For example Tracy explains what the scarring on her hand looked liked below.

Tracy: When you have a full thickness burn, as far as I understand, is you burnt everything, through there. 'Cause it looks like a piece of cooked chicken.

Eva also used a meat metaphor, initially used by one of her health care professionals, to describe her appearance, as evident when she recalls one of her experiences with a nurse.

Eva: 'Oh my god, it looks like raw meat' ((remembering what nurse said)). And I said but that's true, that's what it does look like.

I: So those comments that the nurses made. How did that make you feel in the moment? Eva: Ah, (1) I-I I, they were true you know. And it was probably something a nurse probably shouldn't have said but I, it-it in the in the- it actually didn't bother me that much, it was kind of like Yeah [I: acknowledging that] Yeah, looks pretty bad(:) [I: Yeah] yeah ((slight laugh)) [I: OK]

Although the women presented confident body image narratives outlined earlier, when the transcripts were analyzed using a structural approach by looking at singular words interspersed within larger narratives, a more damaging story emerges. Words that were used when discussing their bodies, included "gross", "not normal" "haggard", "awful" "disease", "meat", "dead", "destroyed", "defect" "shocking" "eye-sore" and "not a pretty sight". These negative words were interspersed throughout the narratives creating an overall negative tone relating to the body.

Thus, as women presented well-adjusted or unaffected narratives overall, subtle nuances of the narratives reveal a negative attitude.

Although the dominant psychological adjustment narratives expressed by the women presented them as well-adjusted and unaffected, subordinate narratives suggested mood changes, self-blame, fear, and decreased activity. Eva talks about how her life is different in that she no longer has the energy to do things she once enjoyed.

Eva: But a lot of times, like people will ask me to do something- In fact I was going to go to (1) hear some chamber music with a girlfriend. And ah (2) and then I just sort thought, you know I'm really tired, I-I just I don't have the energy to. You know, it's dark, it's cold, do I really want to get in my car and (3). And then she says 'I'll pick you up' ((laughs)). I said 'just the thought of it, I'm not gonna do it'. So probably I'm doing, I'm doing less.

Sue came across as one of the most unaffected by her injury even though she was the most severely burned. Earlier in her interview she explained that she was a 'strong women' which prevented her from being affected from her injury; however, the following excerpt reveals some mental difficulty she did face. In the upcoming excerpt Sue discloses "breaking down" but emphasizes that it was only a small number of times. Regardless of the emphasis on only becoming emotional five times, the narrative still invokes a sense of suffering through the repeated use of the word "constant" to describe the mental aggravation.

Sue: No. I don't think I felt sorry. And I only broke down- and maybe that neither here nor there- but I said I don't think I cried five times. And if I did it was five times, but six I know for sure I didn't. And it was just like (2) the <u>constant</u>, the <u>constant</u>, the <u>constant</u>. And it didn't (1) light up, and it didn't light up and you felt like (1) like I think more here ((points in head)) than from here ((referring to the burns)).

Sue, and others, also engaged in self-blame through explaining that the accident was their fault and that they had learnt their lesson. Self-blaming is clearly demonstrated through the following narrative segments presented by two different participants.

Sue: No. Uh-unh. It was my fault ((slight laugh)). I shouldn't have (2) brought the pot out, let the people get sick ((laughing)). So, no uh-unh. I had nobody to blame, just myself.

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I: Do you think your mood has changed since the accident?

Lori: Mm, ah yeah. I'm kind of angry.

I: Yeah (1). What's that anger like?

Lori: Hm, like I get mad and start swearing.

I: You feel like you're getting mad at other people, or you're just mad in general?

Lori: I'm mad at myself.

I: At yourself? Why are you mad at yourself?

Lori: Like (2) like regret and that. For not (1) like I should have been at a different place (2) instead of going to drink.

I: OK. So you blame yourself a little bit for what happened?

Lori: Yeah ((starts crying))

I: Must be really difficult (2) Here's tissue if you like ((long silence to recompose)). What are the tears about?

Lori: (1) Um, (2) like when I was saying like I shouldn't have been there, could have been somewhere m-more (3) like I could have been at my friend's (3) my friends wake ((crying-trembling voice)).

Again, the dominant narrative presented earlier of adjustment and recovery overrides the underdeveloped subordinate narrative presented here. The women had difficulty disclosing their suffering but when asked more direct questions regarding specific difficulties, narratives of self-blame, mood changes, and suffering were revealed.

Interestingly, nearing the end of Holly's interview, after telling narratives that emphasized she was completely unaffected by her burn injury, she broke down into tears when discussing the suffering burn survivors in general experience. The narrative when Holly started crying is somewhat confusing and it seems as though Holly doesn't completely understand the emotions she was experiencing.

I: What would you tell somebody who, let's say is here that just got a burn?

Holly: What would I tell 'em? About a burn, or how to recover from it?

I: Yeah, yeah, both.

Holly: Well, from my perspective and what I believe. Like I believe in prayer very strongly and I think that that was-helped me get the mind set to (1) that I knew it was going to get better. And the pain is (1) temporary ((starts crying)). I would be very emotional with them ((through tears)) you know I don't know (2). I don't know how I would describe it to them, but just to try to encourage them. Tell them to-it's not-it's going to go away. It really will.

But depending on the amount of burn that they would have (2) and the different issues that they would have to deal with, I don't know what I would tell them.

I: What are the tears about?

Holly: (3) I have no idea ((still crying)). I guess maybe because I wouldn't want somebody else (2) to be burnt. (3) ...Um (1) it would, I find it (2) I mean I-I can –if somebody is in an accident or something and I'm right there to help, I can –my-I just go and do what has to be done. Afterwards is when I breakdown. Because I realize the enormity or what may have happened or what did happen. ((blows nose)) Excuse me. Or what (1) um what those people might have to go through. But ah (2) I never want anybody to go through that, but I know it happens ((through tears)) you know, but ah, like you know I said, I have total empathy for anyone that gets burnt.

I: Do you think (2) you know when you get emotional about it and you think how awful it would be if it were somebody else, what's kind of the worse part, do you think (1) of the whole experience?

Holly: Just the initial –the initial-first initial reaction. Um it's like (1) I-you just don't want that to happen to anybody

I: So the pain?

Holly: The emotional pain. The emotional pain for me is (1) um (2) worse than the physical pain.

I: So what's the-what is your emotional pain kind of about or

Holly: Just that I wouldn't want it to happen to anybody else. Like that's what I'm thinking now, might be something else but that's what I'm feeling right now.

I: So it's not really tears for yourself?

Holly: No, for somebody else.

Holly's extreme attitude change near the end of her interview suggests that she was struggling to present herself as doing well and was holding back a certain emotional narrative throughout the interview. She did not express any emotional turmoil when questioned about her injury generally or when probed directly about psychological difficulties or difficulties but in the above excerpt she claims that the emotional pain is worse than the physical pain. Furthermore, when she does start to cry, she continues to suggest that the tears are not because of her own emotional pain but the thought of what *others* may have to endure. Holly's hesitation seemed to recede when she was somewhat removed from the interview process, when she was asked what she would tell other burn survivors about recovery. Seemingly, once Holly was no longer

speaking directly about herself, she was able to express her authentic self through emotion. Her seemingly contradictory and confusing narrative may suggest that it may be difficult to discuss one's own pain and suffering, however empathizing for others is more 'acceptable' or 'easier' emotional reaction. There seems to be the understanding that generally burn injury is a difficult injury to endure and recover from, but it seems it is difficult for the individual to admit she has 'succumbed' to the injury.

Self-Silencing: Reconciling the duality

The two competing narratives outlined above present a seemingly contradictory experience presented by burn survivors. On one hand, the women's dominant narrative presents them as strong and unaffected by their changed bodies while a more subtle storyline reveals pain and suffering. It appeared that certain experiences were not being expressed while others were being overemphasized, leading to disconnected narratives. While personal histories, social locations, and cultural expectations may intersect for each participant in determining what parts of what stories they are willing to share in a one hour interview with a psychological researcher, important insight is gained through exploring the contradiction.

Given that this study involved women and that feminist theories, at their core, assume that examining power and place are essential to understand human behaviour (Fivush, 2004), using a feminist perspective, particularly 'self-silencing' to explore the perplexing narratives will reveal an important and overlooked aspect of women's experiences with burn injury. In this study, the women were able to express their dominant narrative while holding back their narratives of suffering through silencing aspects of their burn injury experience. Jack's (1991) conceptualization of self-silencing is as a cognitive schema that guides behaviour and self-assessment. Although the present study did not explore cognitive schema, it appeared that the

women engaged in behaviours that could be associated with Jack's version of silencing the self. The self-silencing behaviours demonstrated by the women to ensure their subordinate narratives were suppressed were *silencing for the sake of others, silencing by minimizing,* and, *silencing through quest narratives,* all of which are discussed below. Through the use of these techniques the women were able to repress parts of their authentic selves in order to express strength and control.

Silencing for the sake of others.

Women may lose themselves through self-silencing because they try and fit into an image provided by an external source (Jack, 1991). Self-silencing in women is thought to, in part, be employed to maintain relationships with valued others by maintaining the image they believe others expect. Many women explained that they were hesitant to talk to family members, or important others, about their injury. Upon further discussion, it was revealed that these women were concerned about how talking about their injury would negatively affect the other person; women appeared to be putting themselves second. Below, Holly offers a clear example of how many women thought about sharing their experience with family.

Holly: Well I didn't even tell anybody. I didn't even tell my sisters. I got-of course they gave me heck. They said, 'What's the matter? You should have told us'. And I said, 'Well, why? Because it's over with now'. ((Laughs)) I know they're just acting out of interest and concern but.

I: Why do you think you didn't tell them?

Holly: I didn't mind telling the story because I mean, I would have told them anyway. But I didn't want them to worry about it. I guess that's one way of-you hide it because you don't want people to worry about it.

Similarly, the following segment from Sara's interview reiterates how some women hesitated talking about their burn because they did not want to worry other people. In essence, these women were self-silencing and thus being left to worry on their own.

I: Do you talk to anyone about either the pain you're in or the injury?

Sara: Um, just my family but like my best friends know about it and they kind of like-they were pissed off that I didn't tell them right away ((laughing)) because I didn't want them to worry. So, I mean.

What is interesting about the sacrifice the women make for the sake of the other is that the other does not appear to share the same mentality. The other, in fact, was upset by the self-silencing. This would suggest that perhaps the pressure to silence is not coming from significant others but rather a cultural expectation. Jack (1991), in her exploration of self-silencing suggests that, "[g]irls lean early on to create an outer appearance of harmony that will allow the feeling of oneness, of a false intimacy, of a family unit". Perhaps these women feel pressure to maintain harmony with important others by not expressing their pain, suffering, and authentic emotions. By not expressing their difficulties, these women are alleviating others from having to face their difficult emotions, which leave the women to deal with them on their own.

Silencing by minimizing.

Jack (1991) suggests that women may be self-silencing by minimizing themselves through thoughts and behaviours. Women in this study were minimizing in two distinct ways; first, by downplaying their injuries by suggesting that someone else may be worse off and secondly, through emphasizing the importance of physical objects over their own well-being. These two themes will be examined, once again by using a feminist perspective.

With the exception of Lori who suffered burn to her face, each woman emphasized that their injury could have been worse. In doing so, the women appear to be minimizing their injury through not acknowledging that they do have severe burns. In doing so, once again the women are putting themselves second in relation to others-others in this case being hypothetical burn survivors with more severe burns. Evident in the segments to follow, many women

acknowledged that there are people who suffer more than they do which in turn silences parts of their story and seems to minimize their injuries.

Eva: "Even though this was certainly not-in fact after having this-when I read about somebody's got 30% burns to their bodies, I just think oh my god I hope-I hope [I: inaudible] I hope they, you know, that would be something so difficult and I haven't had anything done to my face or anything like that. Ah, that that would be you know, that would be so much more. But you know, it is an interesting thing that, um, everybody says 'well it could be worse' and I said 'yeah, you could say that about everything in life' it could be worse, it could be better too ((laughs)) [I: Right] And, but it is an interesting way of looking at things. You know, could be worse, yes. It could be a hell of a lot worse. ((laughing)) You could even be dead if, it could be that bad".

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Tracy: So, it's I can use my hand. I have haven't lost the use of my hand. And that's all I care about, you know. Other than that, it —why should it affect me? I mean it's not like I've lost any quality of life just because I have a burn. I can use my hand. It was you know little awkward in the beginning, but you know, I can use my hand. It could have been worse. I could have lost my hand ((laughs)) so, so.

This mentality among burn survivors is problematic when the burn literature is considered. Studies, such as Lawrence et al. (1998), suggest that burn injuries may cause significant psychological difficulty, regardless of burn severity. The narratives above seem to suggest that these women feel as though they do not have the right to talk about the hardship they may have experienced due to their burn because there will always be someone worse off. However, the literature would suggest that these women, regardless of the severity of their burn, may suffer psychologically.

The women were also minimizing by placing more emphasis on property or physical objects than on their own bodies and well-being. In many cases, the women in this study sacrificed their bodies to save or prevent further damage to property. Sara, for example, in the following excerpt does not remember the pain and the time of the injury, but does remember trying to save the kitchen.

I: And um what that-I mean what was that experience like for you when you were burned. Was it a lot of pain or?

Sara: Ah I was more probably in shock ((laughing)) I was like 'ohhh'. I was more worried about my kitchen being burned than being burned myself. But my husband was more like, 'why are you trying to be hero for? We could replace that but if you lost a limb or something'. So I was just-it didn't settle in and um like, it just like that day, it just really was stinging so I was more like after, I was like yeah, it hurts. But I was at that time, no I was just worried about, 'Oh I hope my kitchen's OK' ((laughing)).

Additionally, Sue, who ended up suffering 18% TBSA burns, recalls cleaning up before she took care of herself.

Sue: No, the hot broth [I: Broth, OK] from the ham all that grease and everything [I: Right OK]. That's what happened. And I couldn't get up because I have two re-knee replacements and so I had to push like a, you know, (2) athlete and I couldn't get up because every time that I did my hands slipped over the grease so I fell three times back into it until I got it, and I was up. Then I went inside and not thinking about myself. My husband was asleep ha fast asleep, ten o'clock at night um I got up got my ladle and a bowl and scooped up all the stuff back into it because what would my husband do if I went to the hospital and the bees and the wasps were there so I brought it all in, woke him up and he just freaked. So, then I called my son, not thinking, well 911 is easier. But I just called my son and we went to Concordia, and they brought us here. And this was hanging like this ((points to part of skin)) Like just grey skin ((pause)) I was more concerned about the wasps and the bees and what would my husband do.

I: What do you think you husband would do?

Sue: He would leave it there until he came from the hospital and maybe that was next day, evening or whatever and by that time the wasps would be there and, I don't know (1). I just didn't-didn't I mean that part, but that I didn't call the ambulance, that I don't understand. To call my son, he lives six streets over which isn't that far, but (2) I didn't ((laughs))

The preceding narratives exemplify how many of the women put themselves second when in an emergency situation. Both these women, and others not represented here, overemphasized the importance of material objects, such as their kitchens, at the expense of their own body. Putting themselves second seems to be so engrained in these women that even in life-threatening emergency situations, they put their own well-being behind that of material objects.

### Silencing through quest narratives.

The women also frequently used 'quest' narratives in seemingly self-silencing way. Borrowed from Frank (1995), quest narratives involve the women searching and or finding lessons or meanings in their injuries. Frank's use of the term quest narrative is useful in

exploring these stories as he explains quest narratives involve a belief that in the hardship of illness, or in the case burn injury, there is something to be learnt. Although quest narratives are presented as a positive mechanism for coping, these women seem to be using this type of narrative to deny their suffering and are thus self-silencing. Frank explains that, "stories have to repair the damage that illness has done to the ill person's sense of where she is in life and where she may be going" (p. 53). Surprisingly, many participants shared stories of very little suffering, pain, discomfort, or struggle. Considering Frank's interpretation that stories are used to help repair or recover, we could assume that participants are using their stories to move past the burn experience and look to the future, but at the expense of actually acknowledging their suffering.

Many of the participants in this study expressed that their lesson was certainly learnt. Others, in a similar vein, seemed to be looking for reasons or lessons to be learnt, but had not yet found them. For example, in the following segment, Liz explains thinking there must be a reason for her burn injury.

Liz: But I'm like not like 'oh, it's <u>your</u> fault'. Like it happened; I think everything happens for a reason kind of thing. So I'm like it's shitty that it happened to me but I'm like you know, I said after, like I'm glad it happened to <u>me</u> and not her.

I: You said everything happens for a reason. Do you know your reason yet?

Liz: No ((both laughs)). Well I'm hoping there will be some like epiphany, like later that I'll be like 'Ohh yeah!' I don't think that necessarily like, ah, maybe not everything happens for a reason is the right. Like, you know, cause and effect kind of thing, but um more so that it just like, you know, life happens and you have no way of foreseeing what's going to come and you just gotta take it and take it and move on, kind of thing, so.

Liz is using her quest-like narrative here to disregard her pain as suffering and by suggesting that there is good reason for this to happen. She also appears self-sacrificing in the first paragraph when she explains that she is *glad* that she was burned and not her friend. Although this is a selfless notion to express, it depicts a woman willing to take on bodily harm for others.

Sue also expresses a similar desire to find meaning in her injury in the following excerpt.

Sue: I was <u>sick</u>. Is the only way I can say it. And I still don't understand. And if they say everything happens for a good reason maybe I will understand one day but I still don't know. I said I didn't do that much wrong ((laughs))

Others seem to express a more typical quest narrative in that they had learnt their lessons regarding their injury. Holly and Sara's interviews provide exemplary segments of the quest narrative below.

Holly: Oh yeah. Yes. I did learn my lesson. I'm just glad nobody else got hurt. You know, that would have been-I think that really would have bothered me <u>a lot</u> more; to have somebody else get hurt (1) because of my stupidity.

I: But you can live with it that it was you that got hurt?

Holly: Yup. It was my mistake, I learned from it. And I have <u>no</u> intention of repeating it again, for any reason.

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Sara: My mom's like, she called me a little piggy ((laughs)) [I: Why?] That's what you get. Just buy plantain chips at the Chinese store. And I'm like, well I was-I just wanted them then. ((laughs)) So, lesson learned, that's for sure.

Although these narratives present as quest narratives, they are missing a key elements according to Frank's definition of quest narratives, making them in fact silenced narratives.

According to Frank (1995), "the quest hero accepts contingency because the paradox learned on the quest is that surrendering the superficial control of health, yields control of a higher order" (p. 126). Participants seem to want to give control over to a higher power but are lost on that quest. They haven't yet found the meaning or higher power to give over power. Additionally, the boon in quest narratives is characterized by "the body's ability to grasp itself reflectively as a communicative body; to be associated with itself, open to contingency, dyadic towards others, and desiring for itself in relation to others" (p. 127). On the contrary, the women do not seem connected to their bodies in a way that allows them to speak about their experience in great detail and insight. Frank's example of a quest narrative in which the speaker accepts the contingency is reflected in this following quote, "I would have never chosen to be taught this way but I like the changes to me" (p. 128). Again, the participant's narratives contain the

beginning part of this quest narrative-they would not have chosen to be taught this way-but they have not yet grasped the lesson. They fail to acknowledge that they have changed or that they like the changes to themselves. The lessons learnt are very superficial, being mostly regarding lessons about cooking and paying more attention rather than learning something about their character or self.

Some narratives present in this study are silenced quest narrative. The women are trying to present a quest narrative, to appear strong and recovered, however meaningful details are missing. They are using an illusory quest narrative to suppress their current suffering and outwardly depicting a healthy quest narrative. However, they appear to have not yet been through the learning, growing, quest process and remain in silent suffering.

Although not entirely congruent with Jack's (1991) conceptualization of self-silencing, the general concept of self-silencing is useful in understanding the seemingly contradictive narratives the women present in this study. As explained above, the women in this study present seemingly conflicting narratives expressing both full recovery and adjustment to their injury while also divulging body dissatisfaction and psychological upset. In order to negotiate this conflict for themselves, the women appear to use silencing techniques which allow them to predominantly present a strong empowered narrative while suppressing the counter-narrative which may otherwise lead to devaluation of character.

Discussion

The results from this study revealed a complex experience for women following traumatic burn injury. In their dominant narrative, they portrayed themselves as strong, well-adjusted women who experienced little impact from their injury. However, further analysis of the transcripts revealed subordinate, less developed and "thin", narratives which suggested that the

women did experience negative consequences related to their injury. These contradictory narratives resulted in the women having difficulty presenting a coherent storyline of their healing. In order to reconcile their perplexing and contradictive stories, it appeared as though the women employed silencing techniques in order to emphasize their dominant narrative over their subordinate narrative. Although both the dominant and subordinate narratives offer insight into the experience of burn survival, the self-silencing aspect of the narratives is of most significance in terms of both cultural critique and burn care rehabilitation. The self-silencing narrative modes depicted in this study has numerous implications, both in the larger context of women in our culture and in a more specific context of direct burn care. The first requires a discussion about what might drive women to self-silence in our culture and what the repercussions may be. The second requires a discussion about how the study results can help better facilitate psychological adjustment of female survivors of burns.

The self-silencing depicted in this study appears to serve two functions. Firstly, it allows the women to suppress their subordinate narrative, giving it less time and space to develop into a richer narrative, which results in emphasized dominant narratives. In doing so, the women counter the cultural narrative of burn injury and beauty by appearing unaffected, psychologically healthy, and confident with their bodies. With the exception of Tracy who explicitly acknowledges the cultural expectation and rejects it, the majority the women appear to be implicitly resisting the cultural narrative by expressing their 'doing well' narrative in order to resist devaluation based on physical difference. Secondly, the self-silencing may function, on a more personal level, to maintain relationships. In both instances, self-silencing is a cultural phenomena which requires critical evaluation and has vital health implication which requires intervention for improved client care that does not ignore important psychological factors. The

women appeared to not only self-silence in the interviews but also indicated that they self-silenced with friends and family which in turn resulted in the further suppression of their difficulties.

Countering the Cultural Narrative

Feminist theories examine power and place in relation to human behaviour and thus taking a feminist perspective is useful in this discussion. The way in which self-silencing appears in these narratives stresses the negative influence culture has on women in terms of body image dissatisfaction and the right they have to express themselves authentically. Beauvoir (as cited in Tidd, 2004) claims that women do not choose how they 'exist' in their bodies because the 'proper' way to present and experience one's body is culturally defined. The cultural beauty narrative, which embodies women and requires them to be beautiful and flawless, in turn devalues those with non-typical appearances and deems them "not beautiful". Because "beauty" is culturally defined, women have no control over how their bodies are perceived. Recent feminist researchers and writers (e.g., Budgeon, 2003; Gill, 2008; Wolf, 1991) attempt to expose the oppressive nature of this narrative. For example, Budgeon argues,

[w]omen, who have always been more embodied than men because if the association of the feminine with the body, have always been aware of the form and appearance of their bodies and the extent to which they are responsible for creating that surface in accordance with cultural ideals and images. (p. 82).

This quotation emphasizes that women today are held responsible for their appearance based on cultural ideals; ideals which are unrealistic and often unattainable.

Counter to this, the women in this study exerted themselves as strong, unaffected, and unconcerned with their appearance. They denied the importance of their appearance through explaining that their physically disfiguring injuries do not affect their sense of self or body image, do not hinder their social or sexual experiences, and do not cause significant

psychological difficulties. In order to convince the listener of the dominant, 'doing well' narrative the women appeared to repress any suffering or body image dissatisfaction they may have been grappling with in order to present a positive body image and strong dominant narrative. In doing so, they silenced, although did not totally ignore, their subordinate 'suffering' narratives in order to emphasize their dominant narratives and exert control and power over the cultural impetus. This leaves the women caught between two competing narratives; one of strength which resists devaluation of the dominant narrative and one that acknowledges their suffering and allows them to express it.

The resistance of the cultural narrative could be viewed as a stance against the devaluation of women based on physical appearance. The women in this study showed strength and courage in resisting this negative narrative. This is particularly important because women have historically been a subordinate group, lacking power and control, and are now encouraged to be strong and voice their opinions. This demonstration of strength however required the women to suppress other aspects of themselves, their suffering, through self-silencing. Although the women are in one sense resisting this through challenging the cultural narrative, they are still engaging in behaviours that deny other important aspects of their experience. This creates a difficult situation for women as they are caught between speaking out against negative cultural expectations and expressing themselves.

Maintaining Relationships

The women in this study appeared to be putting themselves second, behind significant others, physical objects, and even strangers. For example, women in this study explained that they did not want to worry significant others and thus did not discuss the injury with family or friends. Additionally, the women often placed higher value on their homes and physical

possessions than on their own bodies when recounting the accident which caused the injury. Furthermore, the women minimized their injuries by explaining that "they weren't that bad" when considering someone else could be worse off. These examples are all narrative modes of self-silencing, typical for women in our culture.

Jack and Dill (1992) posit that self-silencing is not a personality trait, but rather a cognitive schema prescribed culturally which then guides women's social behaviour. Self-silencing is thought to be 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 (Jack, 1991). It is argued that women, from a young age, are socialized to be empathic nurturers, placing emphasis on maintaining connected relationship. This explanation 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 part of themselves in order to maintain important relationships. The continuity of the feminine ideal in relationships may be particularly pertinent for women following a burn because the injury can be considered "devaluing". Although they cannot control how they are perceived physically following a burn injury, they may exert more power over how they act which allows them to control the image that is portrayed to others. That is, it may be easier for women to exert their femininity through their relational interactions, than it is to exert the feminine ideal based on their appearance.

Jack (1991) argues that self-silencing develops when women adopt cultural norms regarding 'proper' behaviour that may be inconsistent with their sense of self, thus creating a disconnect between what the women feel or believe and what they express in a social context. Jack further posits that women may lose parts of themselves as they try to adhere to this ideal

image provided by the culture. She is thus suggesting that although self-silencing may benefit relationship, it is only achieved through the loss of self for the women. Although it is unclear whether the women felt a loss of self, it appears as though the women were adhering to cultural norms regarding the 'proper' display of femininity within relationships, primarily through placing themselves second, at the expense of expressing other parts of their experience. Again, a culturally prescribed norm is creating a difficult duality for women and entraps them between placating others to maintain relationships and nurturing themselves.

Both in countering the dominant narrative and by silencing themselves, women are placed in a difficult position; they are caught in a cultural "catch 22". On one hand, they are countering a destructive cultural narrative and expressing a healthy body image and good psychological adjustment, but in doing so, they must silence painful parts of their experience which may lead to further distress. The women's dominant narratives represent women exerting control over their recovery by denying that their body or physical appearance is important but in portraying this confidence, they are left to deal with their suffering in silence in order to maintain a coherent narrative. Additionally, women are socialized to be nurturers and are encouraged to maintain the relationships in their lives at the expense of their own needs. Cramer, Gallant, and Langlois (2005) explain that women are, "caught between a need for close, empathic relationships and living in a culture that does not reward such an orientation, women learn to repress or silence part of their self. In short, self-silencing grows as women adopt cultural schemas about their proper role and behavior in intimate relationships which run counter to their need for connectedness" (p. 582). Gill (2008) realizes this "catch 22" when discussing the tension between culture and subjectivity explaining that women are not portrayed as docile and passive but also not as autonomous and free-choosing. Exposing such contradictions and realizing the

implications it has on women in our society, discussed in the following pages, is essential. Women should be encouraged to be strong and resilient but we, as a culture, also must make allowance for women to experience and express their vulnerabilities.

Limitations and Future Research

In assessing the limitations of this research it is important to keep in mind that qualitative analytic methods do not aim to achieve generalizability and representativeness. Because of the unique sample in this study, it is unknown whether this sample of women is representative of the collective female burn population. Although the sample was diverse in terms of age and cultural background, it is a specific group of participants and thus, it is not clear whether the results from this study can be generalized to the larger burn population. Furthermore, because data was collected from one site, transferability (the applicability of the findings to other samples in other contexts) is limited.

Furthermore, the impact the researcher herself, as a young, unburned, female, had on the participants and their narratives is unknown. The researcher attempted to off-set this limitation through employing neutrality during interviews and by developing rapport with each participant. Moreover, rather than a limitation, researcher characteristics may be seen as part of the research process that should be taken into account in terms of how they contribute to the co-construction of the women's narratives. Therefore, researcher characteristics and the interview context were considered and incorporated into the analysis of the narratives. It must also be noted that participant characteristics play a role in the results that were obtained. For instance, self-selection may have influenced the participants that agreed to participate. For example, perhaps women who felt as though they were unaffected by their injury were more likely to participate and thus

the results emerged as presented above. Alternatively, if more women who were severely depressed or anxious about their injury agreed to participate, the results may have been different.

It is important to address intersectionality; that is, although this study presents the results regarding women's experiences broadly, it does not hold that the experiences and analysis of results carry over to all women. Meaning-making is not only affected by sex, but also age, gender, socio-economic class, and culture. Variation in narrative regarding their experiences did emerge; however, the results presented represent overarching themes found in the interviews to varying degrees. Furthermore, female participants were recruited for the study on the basis of sex. This study did not aim to study gender roles but rather used gender identities and roles as a framework to study burn injury, body image, and psychological outcomes.

Another limitation involves the time since the women's injuries; participants in this sample were between approximately two weeks and one year post injury. It is known that body image and mental health issues have changing trajectories over the first year post injury, creating a unique process. This study captured women's experiences at various times throughout the first year of injury and thus they may have been at different points in their psychological recovery. Additionally, because of the time period addressed in this study, how perceptions of body image or mental health may continue to change after the first year was not addressed, which may have resulted in varying results.

The discussion regarding self-silencing presents a predominantly negative depiction of the phenomenon, suggesting that self-silencing is detrimental to those who do it. The discussion was based on the current literature in the area which focuses on the negative aspect of self-silencing, such as the negative outcomes, most often depression, seen with those who employ the technique. This conceptualization is based primarily on Jack's explanation of the phenomenon;

however the self-silencing in this study may be representative of a different process. That is, it is unclear from the data collected in this study whether or not self-silencing is detrimental. For instance, the women's dominant narratives of adjustment may suggest that the self-silencing detected in their interviews was functioning in a positive way for them. Self-silencing thus could be viewed, based on the data, as a positive coping mechanism which was allowing the women to predominantly feel comfortable with their injuries.

Additionally, the women's subordinate narratives of suffering suggested that they were not in denial about the impact of their injury. That is, they did acknowledge that their bodies look different and that the burn and its recovery had been painful but were able to present a dominant narrative of adjustment. This would support the idea that perhaps self-silencing is a positive coping mechanism allowing the women to move on following a traumatic life event. It is however important to remember that the women also acknowledged that the injury has affected the way they interact with significant others (in that they do self-silence) which also presented within the interviews and that this mode of interaction is mostly associated with negative outcomes. Future research should address the implication of self-silencing specifically concentrating on possible positive aspects of the behaviour.

Lastly, this study used a gendered lens and a social constructivist framework in the analysis and discussion of the results. Had a different lens been used (for example, socioeconomic status, culture, or identity), or a different framework been employed, the results would have certainly been different. Additional insight may be gained through employing differing lenses to interpret the data; nonetheless, the framework and gendered lens used in this study offers a unique perspective on the embodiment of burn injury and has important implications for this population.

Implication derived from this study, discussed to follow, generate interesting possibilities for future research. Because this study is one of the first qualitative studies investigating women's mental health following burn injury, many possibilities exist for expanding on these findings. Potential avenues to explore within qualitative burn research are couples interview or focus group discourse analysis which would incorporate multiple perspectives into one study. Additional possibilities would be to involve participants at different stages of recovery. The current study involved women between two weeks and one year post injury; however, interviewing women who are further along in their recovery or who were burned as children may yield varying results. Furthermore, a longitudinal study would greatly enhance the understanding by assessing body image and mental health processes following burn over time.

Additionally, based on the results from this study, interesting research topics emerge. For example, sexuality was largely ignored in this study, however, with its close link to the body, there is potential for interesting narratives to emerge regarding sexuality. Moreover, considering this study explored the female perspective, it leads nicely into a gender comparison study. Deciphering commonalities and differences between the genders following burn injury will contribute significantly to burn research by isolating gender specific concerns. Additionally, a study involving participants with different types of traumatic injuries or other appearance changing conditions, such as skin disorders, would be useful in isolating burn specific concerns and elaborating findings based on commonalities and differences between groups.

Finally, having brought the potential that participants are self-silencing during interviews to the forefront in this study, attempts to minimize this from occurring within interviews could be made in the future, potentially revealing different stories of recovery. Measures required to minimize self-silencing may involve interviews in contexts where participants feel more

comfortable, such as in their homes, or doing multiple interviews, allowing the participant and interviewer to form a strong rapport before addressing potentially sensitive topics.

Implications

Mental health.

Narratives are important in understanding and expressing oneself but, as these results demonstrate, women are often placed in circumstances that, based on cultural prescriptions, require them to silence certain narratives. Self-silencing behaviours have been shown to be detrimental to those who engage in them as self-silencing has been liked most closely to depression (Gratch, Bassett, Attra, 1995), as well as sexual dysfunction, and eating disorders (Fredrickson & Roberts, 2006). For example, Cramer et al., (2005) found, through structural equation modelling, that with women, depression was directly predicted by self-silencing, selfconcealment, and self-esteem. Similarly, Baker-Miller (as cited in van Daaleen-Smith) argues that authenticity, self-determination, and power are crucial to mental health in that affirmation of emotion is essential in ensuring women express themselves. Other studies would suggest a relationship in the opposite direction with self-silencing promoting depressive symptoms as mediated by self-concealment and self-esteem (Cepeda-Bonito & Short, 1998; Jack, 1991; McGrath et al., 1992). Furthermore, 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 posttraumatic symptoms severity, in a sample of burn survivors (Fauerbach et al., 2009). In short, there is an abundance of research supporting the connection between self-silencing and negative mental health outcomes.

Body image.

It is useful here to refer back to the graph (Figure 1) presented in the introduction which depicts body image satisfaction increasing for women over a one year time period post burn injury. This graph demonstrates that body image dissatisfaction, one of the main psychological concerns following burn injury which appears to be silenced in the current study, worsens over the first six months and stabilizes at a low level (depicted by higher scores on the graph) after one year. When the results depicted in that graph are considered with the results from the current study, important implications are noted. The graph indicates that there are important processes occurring pertaining to body image following burn injury with body dissatisfaction increasing rapidly in the first six months. Furthermore, these findings suggest that body dissatisfaction expressed in this study is not simply due to shock or the need for more time to adjust, but is rather accounting for discontentment in this population. It also suggests that, if self-silencing is occurring in this population, it is not functioning as a positive coping mechanism, but rather self-silencing is allowing for the intensification of body image dissatisfaction over time.

Self-silencing.

Given the impact on mental health and the risk of not fully expressing one's self, self-silencing in burn survivors is an important issue for health care professionals. These results would suggest that female burn survivors may be more willing to acknowledge and express the positive aspects of their recovery with doctors and nurses rather than divulge any pain, concerns, or psychological turmoil they may be experiencing. There may be pressure to be "a good patient" and hopes for a speedy recovery, but it is pertinent that health care providers be open about other, non-physical, problems that may arise. That is, although it is vital that health care

providers are positive and optimistic, it is equally important to initiate conversations about current or potential psychological difficulties that may be faced due to the burn injury.

Summary.

In sum, the current study calls attention to a detrimental cultural phenomenon affecting women in our society. The results indicate need a) for a cultural shift and b) better psychological intervention following burn injury. A cultural shift is a lofty goal and is likely to occur gradually over time as more research is published on the issue. Unfortunately, feminism has lost its motivation in recent years as Wolf (1991) points out, feminism is no longer 'sexy'; and in a culture adhering to the beauty myth, not being sexy is not an appealing option for most. Nonetheless, the cultural narrative is oppressive and detrimental to women and thus questions such as "what is a women's place in her body?", "why do women feel unworthy of other's empathy?", "why is a women's self-identity almost solely based on with her appearance?" and "why do women feel compelled to suppress parts of themselves in close personal relationships?" are important to explore and address in the research arena in order to enable a change in culture's perspective.

A more practical implication of these results is that psychological intervention following burn injury is essential. The main implication for health care providers is to be award that women may not be forthcoming about body image concerns or related mental health issues, as seen in the self-silencing depicted by the women in this study. It is suggested in other research that body image dissatisfaction intensifies as rehabilitation progresses (Thombs et al., 2008), however this study reveals that women are not open to discussing these difficulties which may contribute to the increase in body image dissatisfaction over time. It is thus important for healthcare providers to initiate conversations about possible psychological difficulties that may

arise, encourage women to be open about difficulties they may be experiencing, and encourage them to discuss these difficulties with significant others as rehabilitation continues out of hospital. It may be particularly useful for health care professionals to be cognizant of the various ways women self-silence outlined in this study in order to address the issue directly. Considering the women in this study were not always candid about their difficulties, it may be important to address psychological issues and body image concerns subtly and more than once.

Finally, this research has significant implications for understanding the process of self-silencing in women. Jack (1991) identified and described the phenomenon of self-silencing and this study builds on her work through exploring how exactly women self-silence. In outlining the three narrative modes of self-silencing used by these women, the *way* in which women utilize or engage in this phenomenon is outlined. By gaining insight into the processes through understanding *how* women self-silence, the issue can be more accurately addressed. A more complete understanding of self-silencing may allow for direct interventions which may promote the expression of the self. Developing a greater understanding of this cultural phenomenon is important not only for health care professionals, but also for women themselves who may engage in this potentially distressing process and for their significant others who may, unknowingly, be perpetuating the phenomenon.

Appendix A

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Burn Narratives from Women: Body Image and Psychological Adjustment

Principal Investigator:

Tevya Hunter, B.A., Master's Candidate, Department of Psychology, University of Manitoba Phone: (204) 480-1026

Co-Investigator:

Dr. Maria Medved, Assistant Professor, Department of Psychology, University of Manitoba Phone: (204) 480-1465

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.

Purpose of Study

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 burn injury affects how women experience their body and how this may subsequently affect sexuality, pain, social interaction, and mental health. 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 10 participants will participate in this study.

Study Procedures

Women who are at least 18 years of age and have suffered a burn covering between 5 and 15% of their body can participate in this study.

If you take part in this study, you will have 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) an in-depth interview, lasting approximately 1 hour, about your burn injury will be conducted. 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.

The interview will be conducted in a private room at the hospital and will be tape recorded. Participation in this study will be approximately 1 hour.

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 Spring 2011)

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 anytime with no consequence.

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.

If you want to return to the health Sciences Centre to participate in this study, we will immediately reimburse you for taxi expenses or parking when you provide us with a receipt.

Payment for participation

You will be given \$25.00 per interview visit. You will receive this cash 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. The information will be kept for 7 years after completion of all phases of the study and will be destroyed by June 2017.

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 his/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 follo | w-up in relation to this study, Yes _ No _ | |
|--|--|-------|
| Participant signature | Date | |
| | (day/month/year) | |
| Participant printed name: | | |
| was accurately explained to and appar | mation in the Participant Information and Consent For ently understood by the participant or the participant's hat consent to participate in this study was freely give ally acceptable representative. | S |
| Witness signature | Date | |
| | (day/month/year) | |
| Witness printed name: | | |
| | ed the relevant details of this research study to the hat the participant has understood and has knowingly | given |
| Printed Name: | Date | |
| | (day/month/year) | |
| Signature: | | |
| Role in the study: | | |
| Relationship (if any) to study team me | embers: | |

Appendix B

| <> | Speed up talk |
|--------------------|---|
| >< | Slow down talk |
| [] | Start and end of overlapping speech |
| (2) | Pauses in seconds (here: 2 seconds) |
| (.) | Micro-pause |
| (:) | Prolongation of preceding vowel |
| ((Text)) | Transcriber's comment |
| <u>Underlining</u> | Emphasis |
| CAPITALS | Speech that is louder than surrounding speech |
| - | Utterance interrupted |
| Italics | Increase if pitch |

(Medved & Brockmeier, 2004)²

Appendix C

Demographic and Medical Information

| Demographic Information: |
|---------------------------|
| Participant #: |
| Age: |
| Gender: |
| Cultural Background: |
| Relationship Status: |
| Work History: |
| Return to Work: |
| Education: |
| Others: |
| Medical Information: |
| Date of Injury: |
| Age at Injury: |
| Size of Burn: |
| Hospitalization Duration: |
| Location of Burn: |
| Field Notes: |
| |
| |
| |
| |
| |
| |

Appendix D

Burn Injury Interview Schedule

General:

- 1) Tell me a bit about your burn. How did you get it? What happened to your body?
- 2) What was it like when you were released from the hospital?

Mental Health:

- 3) Has having this injury changed things in your day-to-day life?
 - How so? How do you deal with the changes?
- 4) How is your mood?
- 5) Did you talk to anyone about difficulties you faced after your injury? Any professionals?
- 6) What was challenging or difficult during the healing process? What about during your hospital stay?
- 7) How are you adjusting overall? Anything worrisome going on if your life? Do you have trouble sleeping? Do you think about the accident? What specifically do you think about?
- 8) What would you tell someone else with a burn?

Social Interaction:

- 9) What are others' reactions like to your injury?
 - Your family's reaction? When they first saw you? Is it the same now?
 - How does your community react?
 - Your friend's reactions? When they first saw you? Is it the same now?
 - Strangers' reactions?
 - Children's reactions?

• If scars hidden: Have you shown anyone your scars? Can you describe how it went?

- 10) How do you fell about other people's reactions? Do their reactions influence you or what you do?
- 11) Describe what it's like to be in social situations.
 - Can you think of a particular time when your scars made you feel upset or self-conscious? What was that like?
 - Are there particular situations that make you feel uncomfortable because of your scars? Are there particular situations you avoid because of your scars? Can you tell me about a specific incident?

Pain:

- 12) Are you in pain or discomfort right now?
 - Can you describe it?
 - What is the most painful part? Tell me about it?
 - How are you dealing with it? Can you give an example?
 - How do you express your pain? Do you talk to anyone about it?
- 13) What was it like for you while in the hospital after the injury? How long were you there? What kind of treatments did you receive? How did you feel about the treatment situation? Would you change anything?

Sexuality:

14) Have your relationships changed since the injury? Family, friends. What about intimate relationships?

- 15) I don't know if you've thought about this but what are your feelings and thoughts about being physically intimate?
 - If scars are hidden: Have you shown your scars in an intimate situation? What was it like?

Body Image:

16) Has your injury changed the way you feel about yourself? Your body? Your confidence? Your attractiveness?

Closing:

17) Is there anything you would like to tell me that I haven't asked?

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Footnotes

¹Figure from "From survival to socialization: A longitudinal study of body image in survivors of severe burn injury," by B.D. Thombs, L.D. Notes, J.W. Lawrence, G. Magyar-Russell, M.G. Bresnick, and J.A. Fauerbach, 2008, *Journal of Psychosomatic Research*, 64, p. 208. Copyright [2008] by Elsevier Limited. Reprinted with permission.

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