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Patient Experience Living with Split Thickness Skin Grafts

by

Lindsay Nicole Burnett

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

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Abstract

There is a lack of research exploring the experiences of those living with split thickness skin grafts (STSG). The qualitative methodology of interpretive description (Thorne, 2008) was employed. The process included a single patient interview, coding, describing, and interpreting the data. Participants were selected through purposive sampling and data was collected through in-depth, semi-structured interviews. Data was coded into themes for analysis. Eight male patients and four female patients 20-62 years old ranging 2-29 months post STSG were interviewed. The most significant concerns voiced by patients were identified and organized into five themes: a new normal, split thickness skin graft symptoms, appearance of new skin, coping, and preference to participate in future clinical trials. Patients discussed problems associated with their STSG; these concerns were significant enough to motivate them to participate in future clinical trials using human stem cells.

Keywords: Split Thickness Skin Graft, Scars, Patient Experience, Quality of life

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I thank the Calgary Firefighters' Burn Treatment Society, members from the Calgary Fire Department who are committed to volunteering their time when off duty to raise money for research, equipment, and education to improve all aspects of burn care. The Stem Cell Network, for transcription funding; Alberta Innovates Health Solutions, for seeing the importance of our teams' programme of research, which will enable this study to take place on a larger scale.

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Most of all I thank my patients, for without them this research would not have been possible. A burn injury is a life-changing event that has physical, psychological, social, vocational, and spiritual impact. Each and every day I am grateful to work with this patient population.

Dedication

This thesis is dedicated to my patients, for whom I have the privilege of working with as they move from victim, to survivor

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Epigraph

"Scars are like tattoos- but with better stories" J.R. Martinez

(Trial by Fire: Lives re-forged, 2012)

Chapter 1: Introduction and Background

The quote from J.R. Martinez was taken from a recent documentary that showcases the inspirational journeys of seven burn survivors before and after the traumatic accidents that forever changed their lives and those closest to them. The devastating effects of burns and scars are under appreciated by the public because of their displeasing appearance (Essleman et al., 2001). One of the goals of the producers of this film was to raise public awareness on the tragic nature of burn injuries (Megan Smith-Harris, personal communication, June 8, 2012). In my experience patients have many concerns following a burn injury. They are faced with changes in their body, relationships, and function, which have lasting impact on their psychological, physical, and spiritual well-being.

Despite burn prevention strategies, in North America, an average of one million burn injuries occur annually, approximately 400, 000 of which requires medical care (American Burn Association (ABA), 2012, National Burn Repository). Burn care has evolved significantly over the last 50 years, allowing patients to survive larger, deeper burns. The mortality rate for all burns in North America was reported as 3.7 percent (ABA, 2012). Nearly 70 percent of burn injuries occur in men, with an average age of 32 (ABA, 2012). Moreover, burns most commonly affect young males in their working years. Split thickness skin grafting (STSG) is the most common procedure performed in burn patients as a life saving and quality of life improvement measure (ABA, 2012). STSG is not only a procedure used in burn treatment, but is also used to cover defects following traumatic injuries, cancer reconstructive surgery, and other skin conditions/diseases (Ratner, 1998). As nurses, we need to be cognizant of the differing needs that burn survivors may require. As patients progress through the acute burn phase to rehabilitation,

burn nurses have a unique role in preparing patients for the continuing journey they find themselves on as they reintegrate into society.

Many therapies are emerging with the goal of improving scar outcomes. Stem cell therapy is one area of research that is gaining increased recognition as success in dermal regeneration has been found in the laboratory setting (Biernaskie & Gabriel, 2012). The purpose of this chapter is to describe the pathophysiology of the burn scar, introduce stem cell therapy and its potential role in improving outcomes in STSG. Next I provide a personal forestructure to set the context of the study and to describe the unique role that nurses have caring for patients with split thickness skin grafting (STSG) as they come to terms with the physical and psychological impact of their new skin. This leads to the research questions that I sought to answer, and finally, I briefly introduce the qualitative research methodology used for the inquiry of patients' experiences with STSG.

Pathophysiology of the burn scar

Skin consists of three layers, the epidermis, dermis, and subdermis (Esselman & Moore, 2007). The epidermis is the outmost layer of the skin, ranging in thickness from 0.5 to 1.5 millimeters and serves as a barrier to the environment (Esselman & Moore, 2007). The epidermis contains four distinct cell types known as melanocytes, keratinocytes, Langerhans cells, and Granstein cells (Sherwood, 2004). Melanocytes produce the pigment melanin and are thus responsible for skin colour. Keratinocytes are the most abundant of the epidermal cells, they produce keratin and serve as the outermost protective layer. The Langerhans cells and Granstein cells play an important role in immunity (Sherwood, 2004). Beneath the epidermis lies the dermis, a connective tissue layer that contains many elastin and collagen fibers that provide skin with its characteristic stretch and strength (Esselman & Moore, 2007; Sherwood, 2004).The

dermis has an abundance of blood vessels and specialized nerve endings that provide support and nutrients to the epidermis and maintain the dermal appendages which include hair follicles, sweat glands and sebaceous glands (Esselman & Moore, 2007; Sherwood, 2004). The blood vessels within the dermal layer also play an important role in temperature regulation (Sherwood, 2004). The subdermis, also referred to as the hypodermis or subcutaneous tissue, is the layer beneath the dermis and is composed of dense connective and adipose tissue. This layer is rich in blood vessels, which support the vascular network of the dermis. It also attaches the dermis to underlying structures, aiding in mobility of the skin over underlying structures (Sherwood, 2004).

Wound healing progresses through three phases; the inflammatory phase, typically lasting one to three days, is characterized by platelet aggregation and leukocyte and macrophage migration to the wound site (Gabriel, 2011). The proliferative phase follows and involves angiogenesis, activation of fibroblasts, and collagen deposition ending on approximately day five (Gabriel, 2011; Ladak & Tredget, 2009). Remodelling, takes place over weeks to months following the initial injury as collagen deposition and remodelling of the extracellular matrix occurs (Gabriel, 2011; Ladak & Tredget, 2009). "The desirable result of normal wound healing is replacement of the initial hemostatic with skin that approximates the aesthetic, mechanical, and functional properties of the preinjury tissue" (Gabriel, 2011, p. 302). Research has demonstrated that a wound that spends a prolonged period in the inflammatory phase is more likely to cause hypertrophic scarring, which is an abnormal scar characterized by increased volume, erythema, and altered pigmentation (Gabriel, 2011). It is important to regularly assess wounds, as a wound that takes longer than three weeks to close is also at risk for increased scarring (Gabriel, 2011). Moreover, the patient is at risk for a hypertrophic scar that can be

painful, itchy, have altered sensation, and limited range of motion (Gabriel, 2011). As mentioned, STSG is one of the most common procedures in burn patients to address deep wounds and wounds that will not progress through the normal wound healing phases. Due to the lack of dermis in the STSG, the grafted area can result in a scar that is often problematic with similar concerns as a burn scar that has not been treated surgically.

Stem Cell Research

Stem cells are classified in various ways. According to Burd, Ahmed, Lam, Ayyappan, & Huang (2007) a true stem cell

> must be clonogenic i.e. capable of unlimited self-renewal by symmetric division; it must also be able to divide asymmetrically, with one daughter cell resembling the mother (to perpetuate the clone) but the other capable of giving rise to multiples types of differentiated cells which indeed represent derivatives of all three primitive embryonic germ layers (p. 283).

Stem cell therapy is emerging in many fields, perhaps most widely known from the media attention in spinal cord research. Stem cells have many other real and potential applications, including skin regeneration. Biernaskie et al.'s work (2009) has demonstrated the existence of a dermal stem cell in adult mammalian skin. These dermal stem cells induce hair follicle formation and regeneration and are important for dermal maintenance and repair following injury (Biernaskie et al., 2009). It is important to note that these are adult stem cells:

> An adult stem cell is thought to be an undifferentiated cell, found among differentiated cells in a tissue or organ that can renew itself and can differentiate to yield some or all of the major specialized cell types of the tissue or organ. The primary roles of adult stem cells in a living organism are to maintain and repair the tissue in which they are found (Bethesda, 2012, para. 1).

STSG lack dermis (Crandall & Davis, 2010). As we know, the dermis is important for maintenance of the dermal appendages, which include hair follicles, sweat glands and sebaceous glands. As described previously, this is the reason patients with STSG experience dry, itchy scars

that have abnormal sensation, the absence of hair follicles and reduced function including decreased durability and elasticity of the grafted area (Crandall & Davis, 2010).

Forestructure: Personal

Forestructure is described as "some preliminary understanding of what kind of phenomenon [is being understood] and what possible things might happen to it" (Packer & Addison, 1989, p. 33). In this section, I present where I am positioned as a researcher, including my professional background, and any preconceptions and/or expectations I entered this study. My interest in the topic of burn patients' experiences with STSG developed as a result of my clinical experience. I cared for a variety of adult patients who had sustained accidental and intentional injuries. I had predominantly looked at burn care through a quantitative lens, treating patients' symptoms with medications and open wounds with dressings and creams. When patients were discharged from the burn unit, I had a sense of accomplishment that we did our job and set the patients up for success as they returned to their lives.

The large majority of the burns treated in the burn unit are severe and require STSG. The procedure for grafting includes removing all the burned tissue. Then, the epidermis and superficial dermis are harvested from the donor site, which is an area of uninjured skin. This skin is transplanted to the wound, or recipient site (Fortier & Castiglione, 2012; Snyder, Doyle, & Delbridge, 2001). The donor site heals by re-epitheliazation. For many patients, at least initally, it is the donor site that causes more pain than the recipient site (Synder, Doyle, & Delbridge, 2001). The graft site is covered with a dressing that remains in place for five days, which allows time for the donor skin to adhere and form the necessary vascular networks. After spending five days, most often on bed rest, it was time to take down the dressing. Depending on the location and size of the STSG, this dressing change can be very painful and causes increased anxiety for

patients as their new skin is revealed. The initial appearance of a graft can vary from looking purplish and displeasing to resembling an area similar to the patient's unburned skin. Many patients have a difficult time seeing their "new" skin for the first time, while a select few think it looks good. The best case scenario is that the graft is well adhered with maximum coverage. Although STSG will close the wound, the patient will have a scar that is not the same as his/her previous skin. Once healed, the graft tends to be dry, fragile, painful and itchy (Fortier & Castiglione, 2012; Bell & Gabriel, 2009). Sensation in the grafted areas is also abnormal (Nedelec et al., 2005). The reason for these outcomes is the absence of normal dermal tissue beneath the STSG. These characteristics impact the quality of life of a patient with scars from burns. In my experience, what is acceptable to the health care providers is not always acceptable or comfortable to the patient.

In the inpatient setting we often do not see the end result and do not necessarily understand the importance of positioning and splinting for long-term outcomes. I was fortunate to spend a clinical placement in our outpatient burn clinic under the supervision of the medical director of the clinic. I was able to see many of the patients discharged from the unit. The outpatient volume is also much higher than the inpatient unit enabling me to see many different wounds and gain a deeper understanding of the wound healing process and see how wounds/scars evolve, not always with an acceptable result. In addition to this experience, I have had the privilege of being a member of a laboratory that focuses on tissue regeneration. I have had the opportunity to learn about the science behind skin research, the role and function of adult stem cells, and gain hands on experience by performing STSG on mice and rats through the exposure of ongoing laboratory experiments. I believe it is useful for me to be involved in the basic science and current state of the research field to further understand what therapies may become available to patients. I also

feel my presence is beneficial to the laboratory; the scientists present their research and I present mine which allows us to appreciate the impact we have on the lives of real patients.

In my current role as the Clinical Nurse Educator in the burn unit, I provide orientation to new burn nurses and ongoing education to current burn nurses. There are always new dressings and techniques learned from attending research-based conferences and keeping up to date with the literature to pass on to front line staff. It is through all my experiences that I have been drawn to a more in-depth interest in burn and wound care research. I have always been interested in the quality of life of these patients and often wondered what it is like to live through a traumatic injury such as a burn and the resulting sequalae. These are some of the reasons I have chosen to pursue a master of nursing thesis exploring patient experiences living with STSG.

Research Questions

Due to advances in burn care, individuals are surviving larger, deeper burns, which also results in increased morbidity. We are currently at a state in the field where there has been success in generating dermis (Biernaskie & Gabriel, 2012). The research question I explored was: what is it like to live with a STSG? In order to answer this question and understand the patient's experience with scarring after STSG the following research questions were posed: a) what were patients' expectations prior to receiving a STSG; b) how satisfied are patients with the scar(s) as a result of the STSG; c) what are the most important scar attributes that patients want addressed for future research/clinical trials; and d) what risk are patients willing to take to change their scar(s). These questions are important to prioritize what characteristics are most important to patients to improve.

Theoretical Forestructure

Sally Thorne's (2008) qualitative methodology, interpretive description, was chosen to answer the research questions. It was a good fit to explore the experiences of patients who have undergone STSG, as it encompasses the knowledge nurses bring to the inquiry. Furthermore, the themes that arose from the research data can be applied into practice. This direct knowledge translation capability is useful to nurses working with individuals prior to and following STSG (Thorne, et al, 2004).

Conclusion

In my experience as a burns and plastic surgery nurse, I am able to witness the initial struggles that patients face following a burn or traumatic injury/infection requiring STSG. Once the wounds are closed, the patient leaves the "safe" walls of the unit and faces the world with changes that may never allow them to return to their previous lifestyle. I was interested in what it is like to live with a STSG and what it is these patients have the most concerns about post STSG. As such, I set out to learn what patients expected prior to STSG and after living with the grafts. This data will influence how to prioritize research being done in the laboratory, with the ultimate goal of improving STSG through application of adult dermal stem cells. There are also immediate practical implications of this data for nurses working with individuals requiring STSG. Nursing interventions can potentially improve areas that patients identify as being worrisome through pharmacologic and non-pharmacologic measures. Furthermore, nurses have a unique role in the research of burn survivors, as they provide a bridge between the many health care professionals caring for these patients. It is important, that as clinicians, we take the responsibility to hear what our patients are asking and needing following treatment by listening to their experiences.

This thesis will be presented in five chapters. The present chapter provided an introduction and background of the research topic of STSG. In chapter 2, a review of literature is presented on scar tools and scales, satisfaction with appearance, quality of life (QoL), qualitative burn literature, and stem cell therapy as it relates to this research. Chapter 2 highlights the current gap in research on scars as a result of STSG. In chapter 3 I describe the research method, interpretive description, and provide an overview of the sample, criteria for trustworthiness of the study's findings, and ethical considerations. Chapter 4 includes a discussion of the interview findings and presents an answer to the research question at a descriptive level. Lastly, chapter 5, the discussion, contains a summary of the research findings, study limitations, and implications for nursing practice and further research.

Chapter 2: Review of Literature

There is currently a gap in the literature to address what it is like to like with a STSG. As this literature review will demonstrate, there are many tools and scales to quantitatively measure burn scars. Likewise, there are several QoL measures specific that quantify issues common to burn survivors. There are a few qualitative studies that address body image, returning to life and work after a burn injury, and scars in general, however no qualitative literature was found on the experience of living with a STSG. In order for further improvements to be made in skin and scar research, we must find out what the patients' experiences are living with a STSG and the attributes and problems that are most problematic to the patient. The goal of this literature review is to present the existing literature relevant to this topic and to illustrate how both the available literature, as well as the gaps in this literature, have informed the research questions.

Search Methods

A systematic literature search was conducted through the use of Medline, cumulative index of nursing and allied health literature (CINAHL), PubMed, and Science direct databases. Using the subject headings of burn scar assessment, patient experience and split thickness skin grafting, patient satisfaction with burns scars, burns and qualitative, quality of life and burn injury, and patient experience and burns; the search retrieved zero to thousands of articles depending on the database and subject heading. The search was limited to English and peer reviewed articles. Also included in the review were articles provided by my thesis supervisors. Following removal of duplications, 30 articles were chosen to include in this literature review based on relevance of the subject area being studied. Therefore, articles addressing burn scars, objective scar assessment tools, scar scales, quality of life in burn survivors, and qualitative burn and scar articles were chosen for review.

Non-invasive Measurement Tools

The use of diagnostic tools allows clinicians to assess many burn scar characteristics such as thickness, pigment, and viscoelasticity, which are all important to evaluate evolution of the scar. Nedelec, Correa, Rachelska, Armour, and Lasalle (2008) conducted a study to evaluate the intra-rater reliability and sensitivity and specificity of three diagnostic tools. The Cutometer®, the Mexameter®, and the DermaScan C® were measured against the modified Vancouver Scar Scale (mVSS), a commonly used clinical scale (Nedelec, et al., 2008).

The Mexameter is a device that measures scar color through quantification of the wavelength of light absorbed by melanin and hemoglobin (Gabriel, 2011). Nedelec, et al. (2008) found the tool is unable to characterize normal scar from hypertrophic scar. This is attributed to the fact that other scars, for example a donor site, can become very reddened, but rarely become hypertrophic. Therefore, this device is limited in the usefulness of identifying characteristics specific to hypertrophic scaring.

The Cutometer is an instrument used to assess elasticity of the skin (Nedelec et al., 2008). Based on tissue extensibility, the Cutometer is able to differentiate normal scar from hypertrophic scar. Results of a study by Nedelec et al. (2008) showed a sensitivity of 0.97 and specificity of 0.69, thus it is able to discriminate between normal scar from hypertrophic scar. When the intra-rater reliability was tested, the results were not acceptable. This was attributed to the difficulty relocating the scar with the Cutometer probe, despite strict protocol. Therefore, it is not likely an ideal tool for measuring changes over time (Nedelec, et al., 2008). However, it appears the Cutometer does have a place in differentiating normal outcomes in wound healing from hypertrophic outcomes.

There is strong evidence to support the use of ultrasound in measuring skin thickness. Ultrasound has been used for decades in dermatology for assessing different skin conditions including scleroderma, psoriasis, and soft tissue tumors (Rallan & Harland, 2003). The earliest documented use noted in this review of ultrasound in burn scars was in 1979 by Kalus, Aindow, and Caulfield (1979). It was used to assess the depth of burn wounds in response to an increase number of burn centers employing early excision and grafting. They discovered that ultrasound techniques allowed for identification of both the burn-dermis and dermal-fat boundaries (Kalus, et al., 1979). Since then, several studies have been performed and shown significance in using ultrasound for measuring both scar thickness and assessing burn wound depth during the acute phase of injury. (Alexander & Miller, 1979; Du, et al., 2006; Katz, Frank, Leopold, Wachtel, 1985; Nedelec et al., 2008; Timar-Banu et al., 2001; Van Den Kerckhove, Staes, Flour, Stappaerts, & Boeckx, 2003; Wang, Mill, Kravchuk, & Kimble, 2010)

The DermaScan C is one of the most commonly used ultrasound in the burn literature. It is a high frequency scanner that produces high-resolution images to assess skin thickness (Gabriel, 2011). Timar-Banu, et al. (2001) conducted a study to measure hypertrophic scars using the DermaScan C. They found a statistically significant difference between normal skin thickness and hypertrophic scar. Similarly, Van Den Kerckhove tested 40 burn scar sites. Reproducibility of measurements was evaluated using the interclass correlation coefficient (ICC). The authors found the device had high intra-rater (ICC 0.98), inter-rater (ICC 0.88), and test-rest intra-rater (ICC 0.94) reliability. The intra-rater reliability was further replicated in Nedelec et al.'s (2008) study using the DermaScan C. Findings also showed the device is highly sensitive, specific and has good intra-rater reliability for burn scars (ICC 0.84-0.96). There are no

studies to my knowledge published to date that correlate ultrasound images with skin biopsies in healed burn wounds.

Lau, Li-Tsang, and Zheng (2004) studied the tissue ultrasound palpation system (TUPS) to assess scar thickness. The sample size was 100 subjects, divided equally in burn scars and surgical scars. Three assessors were trained in using the TUPS prior to assessment, while a separate assessor was responsible for rating the scars chosen using the VSS. The results demonstrated test-retest reliability (ICC 0.98) with a high inter-rater reliability (ICC 0.84). Although the results are promising, the authors cautioned that further investigation take place prior to its routine use in scar assessment (Lau, et al., 2005).

Qualitative Scar Assessment Scales

Until now the focus has been quantitative instruments used in burn scar assessment. Although tools are statistically superior, burn therapists also use scar scales as they are quick, cost effective, and allow for assessment of several variables (Brusselaers et al., 2010b) Scar scales were designed to assess subjective parameters, for example colour and texture, in an objective way using a Likert scale (Fearmonti, Bond, Erdmann, & Levinson, 2010). The most common source of error in measuring scars was the ability to relocate the area of the scar being measured. Due to the heterogeneity of burn scars and the lack of precision in measurement, clinical scales suffer from poor inter-rater reliability (Fearmonti, et al., 2010).

The VSS was developed in 1990 by Sullivan and colleagues from the Vancouver General Hospital Burn Unit. The four subscales include pigmentation, vascularity, pliability, and height. Each variable is scored on a scale of zero to three or zero to six, where zero indicates normal skin. Patients were acclimatized to the temperature of the clinic and all pressure garments were removed for a minimum of five minutes as a means to control test conditions (Sullivan, 1990).

The number of assessors was limited to three occupational therapists. Cohen's kappa statistic was used to determine inter-rater reliability. The result was statistically significant and improved with time, which can likely be attributed with increased familiarity with the scale over time (Sullivan, 1990). The authors recognized that their scale was not perfect and suggested that modifications include other attributes of scars such as pain and itch (Sullivan, 1990).

Perhaps the most widely accepted modification of the VSS was done in 2007 by a team of burn therapists from the Health Sciences Centre in Winnipeg, Manitoba. The two disadvantages this team identified with the VSS were the vascularity and colour subsets. They were thought to be highly subjective and did not account for racial skin tone differences (Forbes-Duchart, Marshall, Strock, & Copper, 2009). They developed two color scales, one for Caucasians and one for Aboriginals. Despite the addition of a color scale, the results show color of skin remained difficult to classify. After developing the modified version of the VSS, the main goal of the study was to determine inter-rater reliability of their mVSS. The Spearman Rank Order Correlation test was used to test both total and subset inter-rater scores. All results for the total score from the scale (sum of subscales) were significant ranging from an ICC of 0.81 to 0.89. However, the pigmentation subscale on its own showed poor reliability. Thus the authors recommended having a classification scale with titles "Light", "Medium" and "Dark" skin, which could be used for all races (Forbes-Duchart, 2009). The kappa statistic was used to determine individual subscale correlations between the groups, no significance was found. Therefore, the total scores should be used when determining burn scar outcomes (Forbes-Duchart, 2009).

The Patient and Observer Scar Assessment Scale (POSAS) was developed in 2002 by a group of researchers from the Netherlands. It addresses Sullivan's suggestion to include pain and

itch as part of the scar assessment scale. The scale consists of two sections. The observer scale is completed by the therapist/assessor of the scar and contains seven items: vascularity, pigmentation, thickness, relief, pliability, surface area, and overall opinion. A score of one indicates normal skin and ten denotes the worst scar imaginable (Draaijers et al., 2004). The intra-rater reliability of the observer scale was evaluated using the ICC, with a result of 0.92 (0.87-0.95) when calculated between four observers. This study does not evaluate test-retest reliability or intra-rater reliability. The patient scale requires the patient to assess his or her scar(s). It includes seven questions including pain, pruritus, color, stiffness, thickness, shape, and an overall opinion of the scar compared to normal skin (Draaijers, et al., 2004). Although it includes the patient's assessment of the scar, the items asked may not adequately address the scar characteristics that are important to individual patients. Likewise, this scale was not specifically developed for assessment of burn scars, and was found to be most useful when assessing linear scars (van de Kar et al., 2005).

As with the diagnostic tools described in this review, this is not an exhaustive list of scar scales (Brusselaers et al., 2010a). Moreover, these scales are not specifically developed for assessment of scars from STSG although scars from wounds that heal without a surgical intervention share many characteristics with skin graft outcomes (Van Den Kerckhove, Staes, Flour, Stappaerts, & Boeckx, 2003). There have certainly been many improvements and advancements when it comes to measuring scars. Nonetheless, there remains great opportunity for improvement, ultimately leading to better scar assessment and patient quality of life outcomes.

Satisfaction with appearance

Society places great importance on appearance. Research has shown that more attractive people have advantages over their less attractive counterparts (Thombs et al., 2008) Facial appearance is associated with both internal and external identity. A large component of communication is nonverbal and mediated by facial expression (Sainsbury, 2008) Facial disfigurement may lead to significant emotional distress and social isolation (Egeland, More, Buchan, & Cederna, 2008). The development of contractures and pigmentary changes in the burn scars can significantly alter an individual's appearance (Lawrence, Fauerbach, Heinberg, & Doctor, 2004).

Burn survivors' satisfaction with appearance varies depending on a number of factors; of particular importance is the patient's perception of body image. According to Lawrence, Faurbach, Heinberg, and Doctor (2004) "body image can be understood as a multidimensional concept relating to one's physical appearance and function to body image perception (what I think I look like) and body image satisfaction (how happy I am with how I think I look)" (p. 26). Findings suggest that anatomical location and gender do not necessarily predict how well patients are able to cope (Sainsbury, 2008). In my experience, anatomical location does not have an impact on how patients cope with their burn scars, even if the scars appears minor. Scar management and treatment may have fundamental impact on patients' quality of life. Scars can look displeasing, making it difficult for many burn survivors to interact in the community. According to Thombs, et al. (2008) body image in burn survivors will initially worsen as people struggle to accept new appearance.

Quality of life

The concept of QoL has been studied in health care, and burn patients for over 30 years. In the majority of literature, it is described as encompassing physical, psychological, social, and spiritual aspects of one's life (Meerberg, 1993). It is interpreted objectively, through the use of various established tools, and subjectively, through individuals' descriptions of what QoL means to that individual. "In defining QoL it is important to note that the construct is not static; it is capable of changing dramatically for better or worse over time" (Yoder, Nayback, Gaylord, 2010, p. 1144). It has evolved as a global concept to one with measurable domains (Yoder, Nayback, Gaylord, 2010).

In 1982 Blades and colleagues developed an outcome scale to address the issues common to burn patients. The Burn Specific Health Scale (BSHS) is a 114 item questionnaire. Content validity was established for the scale and demonstrated high reliability for each of the six major domains (Cronbach's alpha 0.55 to 0.92). It was subsequently validated and abbreviated to 80 items by Munster, Horowitz, and Tudahl in 1987. The Burn Specific Health Scale-Abbreviated (BSHS-A) measures four specific domains, three of which have subdomains. The four domains are physical which is divided into mobility/self-care, hand function, and role activities; the psychological domain is divided into body image and affect; the social domain consists of family/friends and sexuality activities; the general domain is intended to capture burn specific impairments such as pain (Yoder, Nayback, Gaylord, 2010). The alpha coefficients for the domains ranged from 0.83 to 0.92, with high intrarater (r= 0.89) and interrater (r= 0.78) reliability (Yoder, Nayback, & Gaylord, 2010). The scale contains a duplicated question and patients that answer with greater than one point difference are supposed to be eliminated from the study (Munster, Horowitz, & Tudahl, 1987). The length of the BSHS-A was thought to be

too long and the BSHS was further revised in 1994 by Blalock and colleagues. The BSHS-R contains 31 items. Cronbach's alpha for the scale ranged from 0.82 to 0.94 (Yoder et al., 2010). The scale did not cover hand function and sexuality, which are specific factors important in QoL for burn survivors (Yoder et al., 2010). Furthermore, Blalock et al. were the only researchers to use the BSHS-R. The most recent modification of the BSHS took place in 2001 by Kildal, Andersson, Fugl-Meyer, Lannerstam, and Gerdin. It contains 40 items and is referred to as the brief version of the BSHS. Cronbach's alpha for the nine domains ranged from 0.75-0.93 (Kildal et al., 2001). Several studies have used variations of the scale and have shown mixed results of QoL in burn patients.

Druery, Brown, & Muller (2005) used the BSHS-A to study patients with total body surface area (TBSA) burns greater than 40 percent. The results showed that burns to the face and hands had a negative effect on physical scores. However, the mental and social domains were not affected by hand and facial burns. This is an interesting finding, as it seems many patients would perceive altered body image and more likeliness of social anxiety if facial burns are present. Similarly, Anzarut, Chen, Shankowsky, & Tredget (2005) studied patients with severe burn injuries with a TBSA greater than 50 percent. The authors compared burns survivors with Canadian heart transplant patients and the general population. They used the BSHS-A to assess function and the Short Form 36 to assess QoL. The clinical variables included the age at the time of injury, TBSA burned, whether or not the injury was work related, the involvement of hands and face, the need for tracheotomy, and the length of stay during hospitalization. The self reported predictor variables studied were mobility, self-care, sexual activity, social support, and body image. The *t* test and chi square analysis were used to evaluate the statistical significance of the results. Findings revealed that TBSA burned, sex, place of injury, facial burns, tracheotomy,

and whether or not the injury was work related are not predictors of QoL. Furthermore, QoL was found to be comparable to the national norms, and when compared with heart transplant patients, burns survivors had a higher quality of life in the domains of physical functioning and bodily pain. Two important predictors of physical QoL were full thickness injury and hand function, and those that required grafting scored lower in this quality of life domain. This finding is important, as a large majority of the patients treated are admitted with deep burns to the hands that require STSG. Nonetheless, results from these studies provide burn clinicians with hope that patients can have a good QoL despite suffering a severe burn injury.

More recent studies reviewed show the majority of burn patients have a poor QoL compared to the general population. Xie, Xiao, Zhu, & Xia (2011) used the BSHS-B to assess QoL on 20 patients with greater than or equal to 70 percent TBSA burns. They found patients scored low in all nine domains, with the lowest scores found in the work, body image, and heat sensitivity domains. Results were not statistically different between males and females. Similarly, Elsherbiny et al (2011) studied 100 patients with burns 25 percent or greater TBSA using the BSHS-B. Findings showed the greatest negative impact on heat sensitivity, work, affect, and body image domains. Therefore, from these studies one would conclude that patients with large burns are concerned about their body image.

It should be noted that the studies that use the BSHS-B found patients had poor QoL, while those using the BSHS-A had a good overall QoL. An additional factor may be the geographical location of the patients. The first two studies were done in Canada while the latter two were from China and Egypt respectively. It is possible that care and cultural norms vary in different countries, and as previously mentioned, it is important to remember that QoL is not static and can change dramatically over time.

The patients' experiences of surviving a burn

Thus far the majority of studies discussed were quantitative. This is due to the fact that few qualitative studies exist exploring the experiences of burn survivors. I would like to highlight six qualitative studies I did review that highlight burn survivors' experiences. Williams, Davey, & Klock-Powell (2003) explored the experiences of eight participants in an effort to understand how burn survivors adapted to their burn injury by studying their experience in the process of recovery including personal and environmental factors that influenced the recovery process. The authors described using a blended qualitative approach drawing on both phenomenology and grounded theory. Based on the data set presented, grounded theory appeared the dominant approach. The themes presented included losses, gains, adaptation, coping with change, and relationships with others. All themes contained several subthemes that emerged from the data. The authors noted the differential outcomes in adaptability and coping depended on when the participant was burned. The authors also noted gender differences and more specifically that men strongly connected to their previous occupational roles. The participants expressed the need to talk and share about their injury, and some claimed they had never been given the opportunity to do so. This finding may resonate with others who have sustained a burn or traumatic injury, however, requires exploring further in future research.

Similarly, Moi and Gjengedal (2008) conducted a phenomenological study to explore 14 adult patients' experience of life after a burn injury. They found the ability of survivors to return to a meaningful life a central theme in the interviews, moreover, "to improve life, it was essential to the process of recovery to strike a balance between acceptance of what could not be changed and efforts to change what was changeable" (p. 1628). The authors describe how rigor was maintained throughout the study process. Moi, Vindenes, and Gjengedal (2008) performed an

additional study to focus on the specific bodily awareness that burn survivors experienced. The authors also interviewed 14 participants. It appears they used the same sample as the previous study as the demographics described are identical. It also seems likely data from the interviews the authors conducted were used for two separate purposes. The findings of this study discussed how the participants experienced their new bodies, which included some discussion of what it is like to live with scars and the symptoms associated with scarring. However, the study provided no direct discussion about scars as a result of STSG, which I have identified in my research study.

Brown, McKenna, Siddhi, McGrouther, and Bayat (2008) interviewed 34 patients to determine the affect scars have on QoL. Although their study is not specific to burn scars or scars from STSG, the findings may be relevant for people who have survived a serious burn. The authors identified five principal scar-related QoL domains that emerged, including physical comfort and functioning, acceptability to others, social functioning, confidence in nature and management of condition, and emotional well being (Brown, et al., 2008). They saw the importance of addressing scar QoL as a component of a comprehensive scar assessment. There are many ways to assess burn scars and there is a growing body of literature to address the need for a reliable, valid, cost effective, and non-invasive tool.

In 2010, Tengvall, Wickman, and Wengstrom conducted a qualitative study to explore 12 adult burn patients' experiences and memories of pain during and after a burn injury. The themes that emerged were becoming aware of pain at the accident, allowing oneself to feel pain, different pain experiences, and perspectives on the trauma. As found with previous studies, the authors noted that patients who reported greater pain during hospitalization also reported poorer adjustment months to years post discharge.

Most recently, Dhal, Wickman, and Wengstrom (2012) studied the unique experiences of patients as they adapted to life after burn injury. The authors interviewed 12 adult burn patients ranging six to twelve months post burn injury. The results were similar to Moi and Gjendedal's (2008) in that patients verbalized having to balance their expectations of what could be changed and what could not following the injury, and moreover the importance of being physically able to participate in daily activities. The authors emphasized the multi-dimensional factors associated with adapting to life after a burn injury and the role that nurses can have to impact the recovery process even after hospitalization. It would seem that that the qualitative studies currently available are transferable to the larger burn population as patients describe many similar experiences seen in the overlapping themes the above authors have identified.

The majority of studies concerned with the scarring following a burn have been focused on quality of life. A paucity of studies have explored any in depth patient experience of living with scars and specifically scars as a result of STSG. In comparison with quantitative research, few qualitative studies exist in the burn literature. All of the above reports vary in focus and provide important knowledge on the experiences of burn survivors post injury. However, of the six qualitative studies that were reviewed, none describe the experience of patients living with STSG.

Stem Cell Research

Whilst STSG has been the main intervention for people with deep burns, new approaches, such as stem cell research (SCR), offer exciting opportunities for improved grafts, which ameliorate some of the current shortcomings that STSG alone has to offer. Few studies have explored patients' understanding of how SCR can contribute to this field. In order for research to move from the laboratory to the patient, it is important to find out if patients would

be willing to accept stem cells. As previously mentioned, experiments are currently being conducted in our laboratory with adult human stem cells; otherwise know as skin derived precursors (SKPs). These experiments are being performed on small rodents, with the goal to be able to transplant autologous human adult SKPs into patients' STSG to regenerate dermis and improve the resulting skin function. It was therefore an important component of my research to determine patient's opinions towards accepting stem cells in a clinical trial that would potentially improve their STSG.

Previous research has explored patients' opinions towards accepting stem cells. For example, Clover et al. (2012) conducted a study looking at the attitudes of 279 patients attending a plastic surgery/burns and medical outpatient clinics. Of the sample, 139 were plastic surgery patients and 140 medical patients. The researchers asked patients if they would be willing to accept tissue engineered skin substitutes derived from autologous, allogeneic, and xenogeneic sources. Of those questioned, 80 percent would be willing to accept a tissue engineered product (p. 312). All participants would prefer autologous cells (92.8 percent), followed by allogeneic, with more acceptance if the cell source was from a family member (90.7 percent) versus a stranger (66.3 percent), and lastly xenogeneic. These results do not lend understanding to the reasons why patients would choose and/or avoid certain treatments. My research has allowed for some insight as to why or why not patients would accept stem cells from various sources.

An additional question important to ask patients in order for new research technology to move forward is the level of preclinical evidence required to translate knowledge from the laboratory to a clinical trial in humans. Kwon et al. (2012) surveyed 214 individuals with spinal cord injuries (SCI) and compared the responses to 235 SCI scientists and clinicians who had completed a previous survey done by the authors in 2010. The SCI patients were asked to

consider what level of evidence would be enough to warrant trying a stem cell therapy (p. 8). Likewise, the SCI researchers were asked to consider the safety and efficacy needed to for stem cell transplantation prior to progressing to a clinical trial. The responses showed that 45 percent of SCI individuals versus 17 percent of SCI researchers believed that rodent studies were sufficient for clinical trials. Following Chi-square analyses the result was found to have a significant difference ($p<0.001$). With respect to large animal studies, 59 percent of SCI individuals and 69 percent of SCI researchers felt this level of evidence was necessary in order to proceed to a clinical trial. Accordingly, Chi-square analysis results were not significantly different. This suggests that nearly half of SCI individuals believe that if preclinical safety and efficacy is found in small animal models, the evidence is sufficient to proceed to a human clinical trial. This is an important finding as many researchers are aware of the time it takes for lab experiments to move forward into clinical trials. This further suggests that the patients are more likely than the researchers to be willing to take a risk to try a new therapy in hopes of improving his/her condition or the attributes and problems associated with a burns scar. It is important to understand how people view their scars using STSG and also their understanding of newer approaches such as Stem Cell research. The question "what risk are you willing to take to change your STSG scar, for example another surgery and/or participate in research?" (Appendices A) was therefore included in this research.

Conclusion

Scars can pose physical limitations, they tend to be dry, itchy, and painful; although they have been shown to improve slightly with time, they remain with the individual for a life, a constant reminder of the injury. The literature review provides an overview of current measurement approaches used to assess scars and quality of life in the burn injured population.

In addition to validating tools and scales used in scar assessment, there is an increased need to focus on including patients' expectations for STSG scar outcomes. Although one study addresses scar-related quality of life, currently there is a gap in the literature that studies the experiences and difficulties for of those living with STSG. Therefore, this research study will add to the current state of skin graft and scar research.

Chapter 3: Methodology

Following the literature review, we know there is a large body of research that addresses the quantitative characteristics of burn scars, however, little is known about how satisfied patients are with their scars as a result of STSG. Therefore, I chose a qualitative approach for this project. Qualitative research allows us not only to determine the "what", but also the "why", as we learn about the meaning participants offer to the phenomena being studied. A qualitative inquiry allows the current gap in the literature to be addressed. This chapter will outline the research design, sample selection, data collection, data analysis, rigour and trustworthiness of the research approach, and lastly ethical considerations, all which will provide an understanding of how this research study was conducted.

Research design

Qualitative research first emerged in the early 1900s. It did not begin to gain approval as a credible and reliable source of truth until the late 1970s (Carper, 1978). While empirical knowing embodies the objective, quantitative domain through the commitment of providing explanations through controlled experiments, Carper describes aesthetic knowing as the framework for qualitative research methodologies (Streubert & Carpenter, 2011). The subjective experience is valued through understanding and interpretation of unique, abstract knowing. "Nurse researchers engaged in qualitative research recognize the subjective reality inherent in the research process and embrace it" (Streubert & Carpenter, 2011, p. 13). We know people understand and live experiences differently, therefore, qualitative researchers do not focus on one truth but, rather many truths (Streubert & Carpenter, 2011). There are many different methods of inquiry in qualitative research, all which have a common goal in seeking to understand a particular phenomenon from the perspective of those who are experiencing the phenomenon

(Morse, 1994), however, the research question and purpose of the inquiry must drive the method, not the other way around (Streubert & Carpenter, 2011).

As mentioned in chapter one, the research question I sought to answer was what is it like to live a STSG? Further questions included: a) what were patients' expectations prior to receiving a STSG; b) how satisfied are patients with the scar(s) as a result of the STSG; c) what are the most important scar attributes that patients want addressed for future research/clinical trials; and d) what risk are patients willing to take to change their scar(s). The research method, interpretive description (ID), was the method of inquiry chosen to explore these questions.

Thorne and colleagues first proposed the qualitative approach known as interpretive description in 1997. It "arose from a need for an applied qualitative research approach that would generate better understanding of complex experiential clinical phenomena within nursing and other professional disciplines concerned with applied health knowledge or questions from the field" (p. 27). The qualitative approach addresses the challenges of traditional assumptions of "truth" and presents a practical method of inquiry in clinical fields such as nursing (Thorne, et al., 2010; Thorne, 2008; Reimer Kirkham, & MacDonald-Emes, 1997). This research design borrows from other methods of inquiry including grounded theory, naturalistic inquiry, and ethnography (Thorne, 2008; Thorne, Reimer Kirkham, & Flynn-Magee, 2004). The purpose of the approach is to immerse oneself in the "field" and to move beyond what is assumed knowledge to see what else might be there. From here, the generation of new insights will allow for translating knowledge and evidence into practice (Thorne, 2008). Thus, the role of the researcher is to account for what is known about the phenomena, to critically reflect on the data gathered through thoughtful analysis, with the purpose of informing practice. For this project,

choosing ID allowed me to gain an understanding of the reality of living with a STSG and furthermore, what attributes patients' would most like changed about the resulting scars.

Thorne, Reimer Kirkham, and MacDonald-Emes (1997) believe "nurses can create sound interpretive description that contributes directly to our understanding of how people experience their health and illness and what nursing can do to make a difference" (p173). This is one of the goals of this research, however not solely to find out what nursing can do, but the entire burn team. It is not one discipline that makes a difference in burn care and outcomes, but rather the overlapping assessments and interventions of the multi-disciplinary team (Al-Mousawi, Mecott-Rivera, Jeschke, & Herndon, 2010). This method was the best approach for my research because I wanted to learn from the experiences of patients living with STSG, and furthermore apply this knowledge to help inform future research and potentially improve the quality of life of these individuals. Conducting a qualitative analysis using ID will also provide our research team with the ability to prioritize future research and clinical trials based on what is most concerning to patients.

Setting

The setting for data collection was a conference room near the outpatient burn clinic. The room used was private with comfortable chairs for sitting. A sign was placed on the closed door to assist in avoiding unnecessary interruptions. One interview took place in the participant's home as per her request.

Sample

In qualitative research, the sample size is often small, especially if data collection takes place in the form of interviews (Streubert & Carpenter, 2011). Recruitment of participants consisted of a purposive sample of adults with STSG who were receiving care at the outpatient

burn clinic. Purposive sampling seeks certain participants based on their experience and/or characteristics (Thorne, 2008). Recruitment was also based on theoretical sampling, which is a non-probability approach where the investigator makes a judgment regarding the participants who will provide the most useful information about the phenomenon being studied. This technique allows for maximum variation to ensure a variety of experiences were documented (Sandelowski, 2000).

For this study, inclusion criteria restricted participants to adults 18-65 years old, the presence of STSG, and English speaking. I chose adult patients as I do not have experience with the pediatric population and adults were easily accessible in my current work setting. I sought to find a male to female ratio that was similar to that of the known burn population. According to the American Burn Association's National Burn Repository, representing statistics from 2002 to 2011, nearly 70 percent of burn patients in the United States were men, and 30 percent female (American Burn Association, 2012). There was no specification for anatomical location of the STSG. English speaking participants were recruited due to the cost and feasibility of having a translator available. The exclusion criteria included skin disorders, major psychiatric disorders, communication, vision, and hearing disorders. It was important that patients did not have pre-existing skin disorders to ensure descriptions were related to the STSG outcome and not other skin conditions. As mentioned earlier, the research had financial constraints; hence patients not able to provide full and informed consent and/or the ability to read and listen were excluded for the study. The resulting sample interviewed consisted of 12 patients 20-62 years old ranging 2-29 months post STSG.

Data collection

After receiving ethics approval from the Conjoint Health Research Ethics Board, recruitment notices were posted in the outpatient burn clinic so interested patients could self refer. Patients

known to the researcher and co-supervisor were invited to participate. Those who provided written, informed consent were invited to participate in a 30 minute interview at a time convenient for the participant. Each participant was assured he/she could stop the interview at any point and likewise could withdraw from the study at any time without it affecting his or her care. Following written consent, verbal consent was affirmed prior to the commencement of each individual interview. All participants were assured their involvement was voluntary and assured of confidentiality both during the research process and for reporting of the results in the form of a thesis and possible manuscript publication. Participants were also provided with my telephone number if emotions were evoked at which time I would have directed them to our burn psychologist. All burns and trauma patients have access to the burn psychologist if they chose to make an appointment. Patients were directed to the emergency department for urgent and emergent issues.

Interview schedule

As previously mentioned, interviews took place in a quiet, private room near the outpatient burn clinic where participants were asked open-ended questions in a non-directive approach. An interview was chosen over other methods, for example a survey or questionnaire, to achieve a better understanding of what it is like to live with a STSG. Guba and Lincoln (1981) support the use of an interview as an appropriate tool as it provides the capacity to tap into the experience of others in their own language, while valuing their belief frameworks, which would be nearly impossible without face-to-face and verbal interaction. The interviews were semi-structured and I used an interview guide to ensure areas of interest were covered (Appendices A), while at the same time, participants were encouraged to talk freely about their experiences of living with STSG. The interview guide I used helped prompt me to ask not only the areas I was

interested in, but also provided cues to keep the interview on track and encouraged open ended questioning. The interview schedule was developed in a way that permitted time between interviews to stop and analyze the data. This time was used to reflect on the similarities and differences participants were telling me, and allowed for preliminary coding of the data. The second portion of the interview focused on opinions towards stem cell therapies. These questions were based on studies by Clover et al., 2012 and Kwon et al., 2011. The questions are important to our overall research program, to determine if patients would be willing to accept stem cells.

Interviews were audio recorded and transcribed verbatim by a hired transcriptionist. Due to time constraints of the research project, it was important to have the data transcribed in a timely manner. Some may argue that the researcher should transcribe the interviews as it allows you to immerse yourself in the data, however having the ability to listen to the recordings and read and re-read transcripts was the best alternative for this project. The cost of the transcriptionist was funded through my co-supervisor's grant.

Reflexivity

Reflexivity is a common term known to qualitative researchers and is a critical component of the research process. According to Jootun and McGhee (2009), it "relates to the degree of influence that the researcher exerts, either intentionally or unintentionally, on the findings. This is crucial in nursing research where the researcher often knows the participants" (p. 42). Reflexivity requires the researcher to document throughout the research process one's biases, preconceived notions, and reactions to the data collected. Doing so became a core element in informing the inductive analytic process (Thorne, 2008) that eventually beame the product or truth in the final report. In providing a forestructure in the introduction, I believe I provide the context of where I am situated in the research based on my past and current

experiences and occupation. This is noted throughout the data analysis to reinforce what I believe to be true based on my preconceived notions and reactions to the data. Thorne (2008) notes a challenge for health clinician researchers, in that many patients may have expectations of what the researcher may offer:

> The researcher is required to find a way to explain the interest in the topic from a professional background, combined with the current role of being the "learner" from the individual who holds the expertise in subjective experience- the patient him or herself. This two-dimensional introduction provides some clarity in both the source of interest in the question and in the expectations for engagement, and permits the researcher to make explicit that the benefit of the research will be knowledge that may help enlighten fellow professionals for the benefit of future patients (p. 111).

I highlighted these elements throughout the research process. In the consent, I emphasize to participants that they are the experts when it comes to living with STSG. During the later part of the interview, when discussing participants' willingness to take further risks to improve their STSG, I make it known that the research is taking place, but we do not have anything novel to offer at this point. Participants provided answers such as " I hope to help future patients", which demonstrated that they realized they may never have the opportunity to benefit from a new therapy and/or treatment.

Thorne (2008) suggests the use of reflective journaling to help guide the research and to document reactivity during the research process. Following each interview I wrote field notes to capture my initial reactions and reflections. As the research was always in the back of my mind, I kept a notebook handy and wrote down any reflective notes or questions that came up. I attempted to use these field notes to reflect on how my clinical experience as a burn nurse could influence the interactions, and how they influenced me. These methods of reflexivity are an

important component of the audit trail, and furthermore central to the rigor and credibility of this research (Koch, 1998; Smith, 2006), which will be discussed shortly.

Data analysis

In qualitative research, data analysis begins during data collection; likewise data collection and data analysis inform one another. The notion of the concurrent process of data collection and analysis of data is well documented in the qualitative literature (Sandelowski, 2000; Thorne, 2008). After each interview I recorded my field notes and stopped to think about the data to think about what participants had told me; this helped shape subsequent interviews. Thorne et al. provides a list of questions that I relied upon as the interviews were analyzed: "Why is this here? Why not something else? What is happening here? (Thorne Kirkham & O'Flynn-Magee, 2004, p. 7). These types of questions were important to consider during and after each interview. The questions also allowed me to revise my interview guide questions, which included rewording, or the inclusion of an additional question or two based on what previous participants discussed.

Consider Wolcott's (1994) statement:

> When you emphasize description, you want your reader to see what you saw. When you emphasize analysis, you want your reader to know what you know. When you emphasize interpretation, you want your reader to understand what you think you yourself have understood. In different ratios, for different purposes, we try to accomplish all three. (Wolcott, 1994, p. 412 as cited in Thorne, 2008).

In order to achieve these goals, I found Morse's set of cognitive processes useful in conceptualizing data analysis. These steps included comprehending, synthesizing, theorizing, and recontextualizing (Morse, 1994).

Comprehending occurs when all is learned about the experiences of participants. It is reached when enough data is collected to be able to write a through and coherent rich description

(Morse, 1994). I achieved this by reading through the transcribed interviews several times, listening to the recordings again, and reading my field notes to understand what participants were saying. I become immersed in the data to interpret the uniqueness of each individual's lived experience. This step required patience and concentration as I learned to understand what participants had told me. During the comprehending stage, codes began to transform from the data.

The second process is referred to as **synthesizing**; here one begins to pull out themes and patterns. Morse (1994) refers to this stage of data analysis as "sifting", where the significant is distinguished from the insignificant data. The transcribed interviews were formatted to allow analysis by presenting the data in a table, with two columns, in a Word file (Appendices B). Data was placed into the table with the interview on the left hand side and room for data analysis on the right. This permitted me to make notes about what I believed the participant had said, and became the basis for interpretive themes. This is where I believe constant comparative analysis also became important. I continually looked at the data to see what participants were saying that was similar and what was different, or individualized for each individual. My supervisor acted as a second coder and re-checked the coding technique and development of themes from each individual transcript. Three additional committee members each independently reviewed the theme development and made amendments through committee meetings where consensus was reached.

The third cognitive process is **theorizing** and requires the development of best assumptions about patient explanations regarding their experiences. For this research, it also meant revisiting the literature to see what other patients living with scars have talked about. I must reiterate that current literature is not available for those living with STSG scars, rather scar

literature is focused on burns/traumatic scars, surgical scars, and/or congenital scars, and there is little qualitative research available. I believe theorizing in ID arises from the actual writing of the interpretations and bringing the data to life.

The last process Morse describes is **recontextualizing**; here the researcher communicates findings that are applicable to other settings and contexts. "This process brings the purely theoretical back to the practical, and permits a full appreciation for the implications of the newly generated knowledge" (Thorne, 2008, p. 166). I showcase this in the discussion chapter, where the experience of those living with STSG is illuminated. This should be the ultimate goal of the research, to translate knowledge into practice.

Rigor & Trustworthiness

Qualitative research has long been criticized for being unscientific and is often not valued in disciplines that rely on objective findings for the primary source of truth. Qualitative research does contribute to knowledge and understanding, and does provide a source of truth through subjective knowing. Whilst quantitative research is concerned with generalizability, qualitative research uses the terms credibility, transferability, dependability, and confirmability. Guba and Lincoln (1981) proposed a model, well known to qualitative researchers today, to assess trustworthiness. It uses four aspects that are relevant to both qualitative and quantitative studies and defines different strategies for assessing both types of research.

Table 1

Comparison of Criteria by Research Approach (Krefting, 1990)

Criterion	Qualitative Approach	Quantitative Approach
Truth value	Credibility	Internal Validity
Applicability	Transferability	External Validity
Consistency	Dependability	Reliability
Neutrality	Confirmability	Objectivity

I would like to turn your attention now to the way in which trustworthiness and rigor was maintained in this research, using the qualitative criteria Lincoln and Guba put forth.

Credibility, comparable to internal validity in quantitative research, is the way in which truth value is evaluated (Lincoln & Guba, 1981). The research is considered credible if others who have endured similar experiences can relate to the interpretations that the researcher has presented (Sandelowski, 1986). Direct quotes from participants are included in the findings to give the reader a deeper understanding of what patients were actually telling me. The credibility of qualitative research is also enhanced through the use of reflexivity (Koch & Harrington, 1998; Krefting, 1990; Sandelowski, 1986), which was described earlier in this chapter, as the importance of me, the researcher, describing and interpreting my experiences and reflections as they developed throughout the research process. Similarly, disciplinary relevance is an important aspect of credibility. As stated by Thorne (2008): "beyond the questions of whether society requires the knowledge we seek, a critique of our research products properly includes the issue of whether the knowledge is appropriate to the development of the disciplinary science" (p. 227). Prior to beginning this research, we knew that patients living with STSG have concerns about the grafts, but we needed to understand what those concerns were and what it is actually like to live with a STSG to inform future research. There is a gap in the literature that addresses STSG outcomes and is important in my area of interest in burns, but also relevant to the larger plastic surgery, dermatology, and other related fields that care for patients with STSG.

Transferability, similar to generalizability, is the relevance to the study to other contexts outside the study (Sandelowski, 1986; Thorne 2008). My sample size of 12 participants was small. However, it represented individuals from various backgrounds with varying injuries and

sizes of STSG. In-depth interviews provided extensive data that was rich in detail about the phenomenon of interest, which was what it is like living with a STSG. Despite the small sample size, this study has the potential to be relevant to other patients with scars from STSG. I must be clear that the goal of this study was not to generalize, but rather demonstrate the knowledge gained as probable truth (Thorne 2008). This truth, although not absolute will contribute to credibility and utility in research and practice.

Dependability, related to the consistency of findings, is the process of inquiry that demonstrates how the interpretations were arrived at, and consists of the thoroughness of the transcripts selected for interpretation. This was achieved by making the audit trail accessible. Lincoln and Guba (1981) describe auditability when the study and its findings can be clearly followed by another researcher and another researcher could arrive at comparable conclusions based on the data collected. I believe other researchers could follow the progression of events in this study by reviewing my documentation in the research process, through the use of reflexivity; including writing field notes and memos, describing how data was grouped, and ensuring supervisors have access to the raw data.

The last criterion, **confirmability**, comparable to objectivity in quantitative research is achieved when the first three criterion described are established (Sandelowki, 1986). It signifies the findings themselves, not to the subjective or objective view of the researcher (Lincoln & Guba, 1981). Ultimately, research trustworthiness and rigor is for the reader to discern.

Ethics

As previously mentioned, this study was approved by the Conjoint Health Research Ethics Board. Participants were given full disclosure, which included an explanation of the study, the right to refuse to participate, my responsibilities as researcher, any risks and benefits in

participating, the right to stop the research at any time, and the procedures used to protect confidentiality (Loiselle & Profetto-McGrath, 2011). Informed consent was obtained and patients were provided with a consent form. Confidentiality was maintained by assigning each participant a pseudonym. The research manuscript contains quotes that do not allow for identification of participants. All identifiers were removed from the transcripts. Audio recordings were converted to zip files and saved on a password protected computer. Recordings were deleted from the recorder following the interview. Zip files were sent securely to a hired transcriptionist.

The nature of the interview had the potential to evoke strong feelings as patients described the events leading up and following STSG. In case of psychological upset, patients were aware they could make an appointment with the burn psychologist, and if urgent or emergent psychological distress, patients were directed to the emergency department for immediate attention. One participant did become teary following the interview, however stated it was good to talk about her recovery and did not wish to seek further help.

Conclusion

This chapter reviewed the design, sample, data collection procedures, analysis, trustworthiness, and ethical considerations of the research conducted. There is currently a gap in the literature that explores what it is like to live with STSG. This chapter allows one to understand how interpretive description is a pragmatic method of inquiry to find out what it is like for patients living with STSG. This methodology helped address the complex nature of living with STSG that enabled me to gain a deeper understanding by listening to the narratives of individuals. The philosophical principles of ID led to the conceptualization that follows in the findings chapte

Chapter Four: Findings

The 12 participants spoke about their challenges and experiences of living with STSG. Using Thorne's interpretative description methodology, I analyzed participants' responses to answer the primary research question of what is it like to live with a split thickness skin graft. The secondary research questions I was interested in included: a) what are the patients expectations prior to receiving a split thickness skin graft (STSG); b) how satisfied are patients with the scar(s) as a result of the STSG; c) what are the most important scar attributes that patients want addressed for future research/clinical trials; and d) what risk are patients willing to take to change their scar(s)? Participants talked about both what it is like living with a burn injury and their experiences of living with STSG. For the purposes of this study, I chose to focus on what it is like to live with STSG.

This chapter begins by introducing the interpretive themes and subthemes that were heard from the data the participants provided. I introduce the participants' demographic information including age, sex, percent total body surface area injured at the time of the injury, the mechanism of injury, and the number of months since STSG. Next, I present two interviews that serve as exemplary cases of the study. Lastly, I discuss the interpretive themes and sub-themes, which included both the unique and common experiences of the participants. Verbatim quotations are used to exemplify the themes and sub-themes. Certain elements of the interview have been omitted to protect the patients' and health care providers' identity to comply with the confidentiality agreement. Some quotations have been edited marginally to ease readability, for example excessive "ums", "hmmm" and other speech space fillers were removed. Editorial deletions are denoted by "…" in order to understand where there was a pause between thoughts.

Interpretive Themes

Thorne (2004) suggests that the emergent patterns and themes should be ordered so that we "might make sense of the most important ideas to be conveyed and access their meaning in a new manner" (p.15). Drawing upon these principles, significant concepts inherent to the study that emerged from analysis of the interview data experienced by the 12 participants are presented in Table 2.

Table 2

Interpretive Themes and Sub-themes

Theme	Sub-themes
A new normal	
Physical symptoms of STSG	Itch and Dryness Pain Altered Sensation Function of the STSG
Appearance of new skin	Color and Texture Visibility of STSG scar
Coping	Social Support (friends, family, peer support) Time It could have been worse
Participating in future clinical trials	

These five interpretative themes are presented in the remainder of this chapter. Some themes are comprised of sub-themes, which represent common characteristics and contextual meanings within the underlying theme (Lincoln & Guba, 1985).

Introduction to the participants

Participants ranged in age from 20 to 62 years old and were living with STSG 2 to 29 months prior to the interviews. The sample included 8 males and 4 females. The participants had different reasons for requiring their STSG, with deep burns being the most common reason. One

participant suffered necrotizing fasciitis and one polytrauma. The purpose of the study is not to explore burn scars in general, but outcomes of STSG.

In order to provide context to the data, I am going to present two exemplary cases that I feel illuminated what it is truly like to live through an injury requiring STSG, recover from that surgery, and transition into life as a survivor. Thorne supports the use of exemplary cases to capture commonalties and individual variations within the human subjective experience (Thorne, 2008, p. 185). The participants were chosen, not only based on their rich descriptions of their experiences and resulting data, but also to highlight that experiences were similar, yet unique for patients at different stages of recovery, different TBSA injured, age, and sex. Furthermore, following analysis of all interviews, the themes that became apparent were exemplified in the two prototypical cases of Travis and Jane.

Travis, a 24-year-old male, sustained chemical burns to 40 percent of his body while on the job. This happening 10 months ago and he still recalled the pain vividly, grimacing as he told me each painful detail of that awful day. A day he now wishes he had no memory of.
Travis spent just over three weeks in the intensive care unit, after which he was admitted to the inpatient burn unit.

Pain was a theme heard throughout the interview. The pain manifested both physically and psychologically as he relived the events of the accident. He provided insight into feelings of anxiety and fear during the time in hospital. He talked about therapy being a highlight of the day, as it was a means to getting out of his room. A lot of painful activities occurred in the patient's room, and although the room can be considered a safe place, it also gets associated with many painful experiences that must take place, for example dressing changes.

Travis shared his experiences of having surgery and seeing his STSG for the first time. He talked about having high expectations and wanting the skin to be as close to normal as possible. When asked what it was like to see his STSG for the first time, he recalled:

> It was scary. Super scary. And even seeing them for the first time, they were all covered with stitches and staples and a million miles of bandages wrapped around it. Yeah, it was hard. Especially lying there. You know that it's going to be like that forever. That was pretty hard to handle – like you are never going to be like you were before. That part was tricky. It was pretty scary.

Travis talked about how others told him the STSG looked good, and this gave him hope and a provided a reminder that things could have been a lot worse. He did, however comment: "I didn't really know what that meant, I didn't know what a bad one looked like. To me it looked bad all the time". The participant further talked about some of the STSG as being thick, swollen, hard, and the desire to have them back to as normal as possible. He talked about the change in sensation over the STSG areas, describing some areas as having increased sensitivity and some having less:

> It is really hard to explain the surface sensitivity because at first it felt like you were wearing a glove all the time, like a rubber glove. You could feel the pressure but not so much the skin sensitivity…if you banged them it would hurt way more than normal…but you didn't have the surface sensitivity as if you were to touch them or something. You could drag your hand across there and I wouldn't even know.

He also talked about the dryness and itchiness: "initially I had a lot of issues with the itchiness and I kind of just got used to it", thus showing this symptom improved over time. He spoke about the motivation he carried from within in order to achieve the best possible outcome through long, intense hours of physical and occupational therapy.

Although Travis talked about wanting the STSG to be as close to normal as possible and initially thinking the appearance was undesirable, he later talked about being "extremely happy with them" and liking the appearance. He went on to say: "I think it kind of shapes who I am

now". This notion of getting used to the new skin and accepting a *new normal* is heard through the remainder of the interview. He talked about overcoming the functional limitations and how many of the symptoms have improved with time. When asked if he could change one thing about the STSG, he stated:

> The elasticity. I think that was the hardest thing that I struggled with, just working to get that range of motion back. If there would be any kind of way that you could make them a little more elastic, like real skin, that would be a huge thing, and I know that is probably about 90% of the answers.

He talked about how after stretching the STSG and burn scars for hours every day, only slow progressive gains are made. Furthermore, if he misses a couple of days stretching, it is noticeable and his skin becomes tight easily. He described the tightest areas to be in regions where the grafts did not adhere and heal, otherwise known as "take". When I explored his thoughts about 'risk' and what he would hypothetically be willing to risk for his skin he is adamant it would be 'non-invasive therapy not surgery'. He talked about the long healing process he had already endured, and that a surgery would not be his first choice. When asked about his opinion towards accepting stem cells, he would prefer his own versus another person's cells, and was not sure about receiving stem cells from an animal source. Lastly, when asked about his opinion on the level of evidence he feels necessary to proceed to human clinical trials, Travis expected the results to be consistent prior to human experiments, and also stated:

> I mean, if I can help, even myself personally, if I could help make a difference for other people in the future, to not have to go through some of the stuff that I have gone through and more so people that I have seen go through, I had a pretty high success rate, but if it would be beneficial for other people in the future, I would probably be . . . I would try something like that.

From this statement, it is clear Travis wanted to help other people so they do not have to endure the pain and suffering he has coped with, and furthermore, live with the unpleasant effects of the

STSG, burn scars, and limitations he currently faces. Travis' story of his burn injury and recovery invites us to gain a deeper understanding of what it is like to live with a STSG. He shared the symptoms he experiences, what it means to have a changed appearance, and furthermore, we learned that he would be willing to participate in a minimally invasive clinical trial that would involve the use of autologous stem cells to improve his STSG.

Whilst Travis's story exemplified the process of returning to a *new normal* and many of the themes inherent in the experience of a burn patient, Jane's story exemplifies the process of healing following a motor vehicle accident that resulted in flame burns to 30 percent of her body. She shared the struggles and successes that have lead to an acceptance of her changed life situation. The original injury took place 22 months prior to the interview, with the last STSG surgery taking place 12 months prior to the interview. This is the only interview in this study that took place in the participant's home. She appeared relaxed having the interview in a setting that was comfortable for her and spoke freely about the accident and the losses she endured. She admitted she was not able to talk about many aspects about the accident until recently, and stated that "time heals". She also states "it's just now that it doesn't make us cry when we talk about what happened in the first little while of the injury". Jane shared her experience she had spending seven weeks in hospital and the importance of her family as she recovered in and out of hospital. Upon discharge, the patient moved cities to live with her family, which helped her cope with the injury and losses she had experienced.

Jane described her care in hospital being "very good". She spent approximately a week in the intensive care unit and admitted in the initial weeks of they injury "they had me very heavily sedated". She therefore had little recollection of being told about her injuries or pre-surgical discussions from health care providers, "a lot of the information came from my family".

Following her STSG surgery she talked about the pain in the donor sites, and described them as being "more painful than the burn sites".

Jane talked at length about her appearance. She admitted not looking in the mirror during the hospitalization. She described the first time seeing her burn scars and STSG: as "...very emotional. I did not understand the extent of my injuries…" She further described an experience in hospital where a nurse was trying to wash her hair, about six weeks post injury, and found a large burn on her scalp. This burn was deep and required STSG; because the first graft did not take well, she required a second STSG. At the time of the interview, Jane continued to experience many unpleasant outcomes associated with the STSG. In the early months, Jane talked about the importance of having her grandson, Paul, as a distraction, while at the same time talked about how this enabled her to stay in the house so she did not have to be seen in public:

> He [grandson] didn't know me any other way. So he didn't question. He doesn't look at me and say, what's that Nana? You know, so I can go around the house without… but for the longest time, I didn't even like having my head exposed to my family. I would wear a little, you know, just some kind of a little scarf or something around my head, even in the house, 'cause I just didn't, I was very self-conscious about…my head.

She further described how skin is the first thing a person sees, and the importance of hair to a woman's whole look. She also described the increased fragility of the STSG on her scalp to be the most problematic and concerning attribute of the STSG. Other STSG symptoms that were explained as troubling for the participant were the itchiness, increased sensitivity and decreased elasticity of the STSG areas. She also described a related symptom of increased perspiration to her forehead that was not a problem prior to her burn injury. She attributed this to the loss of sweat glands in her STSG.

Jane made many references to the coping processes she endured over the last two years. It seems she has now reached acceptance with her injury as she discusses the fact that "it could

have been worse"; she is focused on what she does have and is able to look into the future: "there is going to be a life after recovery and my life will go on". After considering the coping that has taken place with the help of support and time, the participant goes on to talk about the *new normal* she is now faced with. She talks about how she shops for scarfs, hats, and wigs to cover up the STSG scarring on her scalp, how she attends burn survivor meetings, and furthermore, how she is trying a resume a life for herself.

This participant continues to struggle with the open wounds on her scalp and would be willing to consider procedures to having a better looking and functioning STSG: "the thought of being able to grow hair again and having the sweat glands, like it's just – yeah, it would be just absolutely wonderful." Her face lit up at the thought. When asked about the source of stem cells, this participant preferred autologous, but would be willing to consider allogeniec and other human tissues if provided informed consent.

Similar to Travis, Jane's story illuminates the experience of living through a burn injury, the surgeries and resulting scars, and changes that took place to adapt to her new life. Both participants shared similarities in the STSG symptoms they suffered, but also had unique experiences that emphasized healing following a traumatic injury is highly individualized and influenced by a number of contextual factors. The remainder of this chapter highlights the themes and subthemes that were evident in Travis and Jane's stories, and also in the other 10 participants that were interviewed for this study.

A new normal

All participants sustained an incident severe enough to require STSG, and all participants regardless of the severity of injury, spoke about the life changes they were faced with. A salient theme that arose when talking to the survivors was adjusting to life after the injury, or as one

participant phrased it as a *new normal,* which is where the theme originated: "I'm really working hard at getting back to, you know, it's always going to be *a new normal*, but I'm trying to, yes, resume a life for myself" (Jane). Upon analyzing the other interviews, this theme reappeared many times. As Travis describes it: "you know that it's going to be like that forever. That was pretty hard to handle – like you are never going to be like you were before. That part was tricky. It was pretty scary" . Another participant explained:

> They said it would be different than normal skin. They said it would be a bit rougher and a different color but that's all I remember… I wasn't okay with it but it had to be done. I accepted the fact that I am going to have that and I can't have anything else. I can't just let my skin rot. (Cindy)

Participants also described the increased time needed to care for the STSG. The reality of living with a STSG involves more care and attention of the new skin. One participant described the process of caring for the STSG and pressure garments taking approximately two hours, whereas prior to the injury he would spend less than 45 minutes to prepare for the day. He refered to this *new normal* as a part time job. Similarly, another participant talked about how she has learned to live with the changes in her life: "…A normal person, well a person without skin grafts, they don't worry about stretching their skin, they worry about stretching their muscles and their ligaments"…, "I've learned to live with it" (Cindy). Lastly, I want to share another participant's account for embracing his *new normal*:

> Even minus the big toe, it hasn't slowed me down. I can swim. I can walk. I haven't tried jogging or bike ridding, but that'll happen in the near future… I haven't got any disabilities in my opinion. It takes me longer to do a few things… but not a concern. (James).

Throughout the interviews, the concept of normal arose many times. This notion of normal is likely a reference point to the past. For example, "the sensation is not normal", this patient is comparing the present to the past. Likewise, when one says it does not look normal, he/she is

most likely comparing the skin's properties to that prior to the injury. Normal is also an individual term, what one person thinks is normal may not be seen as normal to someone else. It was most intriguing to hear patients begin to describe a new normal. For many participants, I heard this as adjusting to the injury in a positive way.

The physical symptoms of STSG

All of the participants in this study had at least one symptom of his/her STSG that was problematic. The length of time since the last STSG surgery did not seem to impact whether patients experienced specific symptoms, and furthermore, symptoms continued to exist even years following STSG. The physical symptoms participants experienced were divided into four sub-themes: (a) itchiness and dryness, (b) pain, (c) altered sensation, and (d) function, which was further classified as elasticity and fragility.

Itchiness and Dryness.

Five participants described the symptom of itch as being a concern. One participant prioritized itch as the most concerning outcome of his STSG. His description of living with the uncomfortable sensation was apparent in the ways he tried to cope with the itch of his STSG: "I itch it, pinch it, pour water on it. I ice it a lot…icing does not really help it, but it kind of numbs it to the point where you don't have to itch it anymore" (John). He continues to take a prescription medication, gabapentin, to help with the constant pruritus. Another participant spoke about a similar experience with itch and also takes gabapentin: "the itchiness is everywhere, but the thighs are the most prominent…they [the scars] have got really thick" (Chris). Living with the itch was often described in relation to dryness:

> "I don't go without lotion. I can see it getting itchy if there wasn't any lotion on. Even if I get out of the shower and, say, put my makeup on or something, if I wait a little bit before

> I put lotion on, I can see where it would get itchy, 'cause it gets a little bit itchy if I wait even 10 minutes (Jane).

Other participants also described their experiences of itchiness if the STSG was dry for example, "they tend to be itchy but as soon as I wash my hands and put moisturizer on them they are not itchy anymore" (Ian). Participants described the extra attention required to moisturize and a conscious effort not to scratch as doing so puts them at risk for opening the wounds. Similarly, too much moisturizing can also cause skin breakdown Thus, it is a delicate balance: "dryness can be a problem and, again, in the areas where there are wounds, dryness is a never-ending battle to keep it wet or dry or back and forth"(James). The importance of the symptom of itch must be acknowledged as it can affect an individual's ability to sleep and participate in previous activities, as one participant stated: "mainly it's in the middle of the night, you know, at 2 o'clock in the morning, it will wake me up itchy" (Robert).

Pain.

All but one participant spoke about having some pain, with a range from mild to severe. Matthew's burn experience is unique compared to the other participants as he suffered a spinal cord injury leaving him a quadriplegic prior to the burn injury. Although he described having some sensation to his lower extremities, he was not able to feel extremes in temperature and stated he has a high pain threshold. He shared that he "was surprised when they [nurses] offered it [pain medication]" (Matthew).

The participants talked about their pain experiences from physical, mental, emotional, and spiritual ways. Pain was not always labelled as such, but was heard through the body language, words, and tone of the stories being shared. Although the concept of pain emerged in all of the interviews, none of the participants described pain as being severe in the STSG itself.

For many, it was the burn injury or donor site that caused the most physical pain. One participant talked at length about her pain experience while in hospital being difficult to manage, "there were times where I would be crying and screaming and just in so much pain that no medication could do it [help with pain]". For Cindy, when all pharmacologic options had been exhausted, the burn team chose to try guided imagery. The participant's account of the use of guided imagery was as follows:

> …when dressing changes were to happen, I would do that, like half an hour before to just calm myself and get me to that place where I was hypnotized again. And that helped a lot better than any medication that I had. (Cindy).

The participant used this method for coping with pain following discharge.

If possible, patients are treated as outpatients. The two most common reasons for admission from the outpatient department are to have surgery and for uncontrolled pain, which often results in surgical intervention. Two of the participants were originally treated as outpatients. Each was admitted for the above reasons. As one patient recalls:

> I think the pain was too much and I couldn't even walk at that time. I came back, so they suggested for me to stay in the hospital because they told me that it will be difficult for me if I stay at home (Sarah).

Both patients admitted to the burn unit went on to have STSG for deep burn wounds. All of the participants in this study described pain. During the interviews it did not appear anyone was experiencing physical pain, and the majority of patients admitted pain was no longer a problem.

Altered Sensation.

Pain and itch were described as distinct sensations that all the participants experienced at some point during their hospitalization and recovery. The majority of participants reported other altered sensations of the STSG. Some individuals struggled with the hypersensitivity, while others described a lack of sensation, or numb feeling. A few participants admitted to dealing with

both hypersensitive and hyposensitive areas within the same grafted region. These symptoms can make it difficult to perform daily activities and require the individual to have increased awareness in terms of exposure to controlled temperatures: “for temperature for water and stuff, I have to check with my forearm…there’s a couple of times it has been really, really hot and I have had my hands washing and then if it touches my wrist, I would be like, whoa, that’s really hot” (Ian). Participants did speak about the need to be more careful when performing previous activities, not only because of the risk of discomfort or pain, but also due to the heightened awareness of possible injury. Several participants described having no feeling over a large portion of the graft: “I have no feeling. The feeling stops about half an inch on the good side of the seam of the scar all the way around” (Patrick). One participant was very animated when he talked about the increased sensitivity, and it was clear even light touch caused a hypersensitive reaction: “oh, they’re hypersensitive, my arms… when someone else is putting the cream on, I just go (grimaces)…I just touch something and I go ohhh!”(Robert). Another participant talked about how the increased sensitivity is painful: “this hand, it’s got a lot of thick areas and it’s a lot more sensitive, especially this area and just where it went over the knuckle is more sensitive…more, well, painful than sensitive” (Chris). Altered sensation remained an issue for nearly all participants at the time of the interview.

Function.

Participants described problems with the functional outcomes of their STSG in two main ways. The first was related to the decreased elasticity of the STSG and the second was described as increased fragility of the STSG. The decreased elasticity was depicted as affecting range of motion, while the increased fragility of the skin posed problems for open wounds. Seven participants spoke about these problems and the affect wound breakdown had on their daily

lives: “one day I was wearing sandals without socks and in the area of my ankle, just the strap on the sandals seemed to rub the skin and the next thing you know there were some open wounds” (James). Two participants talked about the resulting contractures and one patient was booked for a surgical release at the time of the interview. Whereas the thicker areas of STSG scar were associated with decreased range of motion, elasticity and hypersensitivity, the thinner areas were associated with open wounds. Two participants talked about their concerns of contracting an infection related to the open wounds. One participant shared: “I hate the open wounds. They really, really bother me…having had an infection was a problem, having open wounds is paranoia” (Patrick). Both participants had prior experiences with infection. For young adults in the workplace, the outcomes of STSG can affect the job they are able to perform. One participant shared the increased awareness required:

> …I was working on an old project car…I can’t just stick my hand where I can’t see it, so I have to look around and see if there is anything sharp. Before I could just stick in there and if it got scratched I wouldn’t care (Ian).

Likewise, decreased function affected the ability to participate in leisure activities: “the extension you used to have with normal skin, it’s not there anymore. There’s no power…Stick handling with a hockey stick, when you have to drop your left hand, to stick handle with one hand, it limits a lot and it’s just very frustrating” (John). This participant had prioritized function and numbness as the most problematic attributes of his STSG. Participants described the importance physiotherapy and occupational therapy played in improving function: “the stretches help enormously” (Patrick). Furthermore, they talked about how quickly function was lost if inadequate time was devoted to therapy.

The theme, physical symptoms of STSG, was heard by every participant as he/she described individual concerns which were represented as sub-themes of itchiness, dryness,

altered sensation, pain, elasticity, and fragility. The symptoms can be distressing, affect quality of life, and the ability to return to work and leisure activities. This theme identified a gap in the current literature that describes symptoms specifically experienced as a result of STSG.

Appearance of new skin

All of the participants spoke openly about the appearance of his/her STSG. As Jane pointed out: "skin is the first thing that people see when they look at you". The subthemes that emerged within this theme were a) colour and texture; and b) visibility of the STSG.

Colour and Texture.

For some participants, the change in colour of the STSG was the concern, for others it was the texture and unevenness, and for some it was both. To illustrate, Cindy shared her feelings on how her STSG looks: "it's rough…it's bumpy, it's hard, it's discoloured and it's not really the prettiest thing ever". For several individuals the fact that the new skin looked different from their uninjured skin caused uneasiness. One participant shared: "it's not only color, it's just the looks of it; too many holes, too many imperfections and it is very frustrating when you go out" (John), similarly, Judy shared: "it doesn't look normal…you don't what is going to happen, how it is going to heal. That is the scary part".

Visibility of the STSG.

Visible scarring was worrisome to some of the participants, and as a result they made an effort to cover up the scars: "with a glove I almost feel more confident" (John). Having the ability to cover up the visible scars helps makes this patient more comfortable in being seen in public. Another participant spoke about the anatomical location as an advantage:

> It's in the best spot to have I think because it's always going to be covered. But if it was on my face or my arm or my leg, I think I would be a little bit more sensitive about having them. (Cindy)

Likewise another participant made a similar claim:

> Some burns, facial burns or different arms where fingernails are burnt off or earlobes are burnt off, that's I think a little harder to swallow but my burn and my ability to walk… unless I said to somebody I got burnt on the leg, they wouldn't have a clue right now. (James)

Similarly, a different participant makes reference to facial burns likely being more difficult to cope with:

> …like if I had to get something grafted on my face, then it would make me feel a little more awkward 'cause then if it didn't go back people would be staring at it and all that stuff . . . but most of my injuries, other than my two hands, are under my clothes. (Chris)

Clearly, anatomical location impacted each participant's perception of his/her STSG scars and furthermore, having scars that can be hidden made it somewhat easier to accept the appearance than if scars were visible.

When explicitly asked about the appearance of the STSG, some participants said appearance was not a concern, yet at some point during the interview, with the exception of one participant, all made references that implied their altered appearance was bothersome. For example, one participant talked about the looks not mattering, and that function was more important, however later in the interview when asked about the priority concern of the STSG, he stated he would change the appearance. He would like the STSG colour to be closer to his native skin and have "less wrinkles" (Ian). In contrast James shared: "I think the medical art of skin grafting is working. I'm pleased with it. I think my appearance is getting better every week, every month…". When Matthew, the quadriplegic participant, spoke about appearance, he described a unique difference: "people don't generally ask about things appearance-wise, I find, when you are in a chair. They really don't want to know the answer" (Matthew). This

participant's STSG was hidden; it would have been interesting to see if he would have answered the same if the scars were visible.

Although appearance seemed important for the majority of participants, when asked "if you could change one thing about your STSG, what would it be?", only three individuals choose appearance as a priority concern. There are a variety of possible explanations for this finding. For some participants, other STSG symptoms were more distressing and a priority to improve, while others admitted they were getting used to the altered appearance and had accepted the outcome. This process of acceptance takes place through coping, which is described in the following section.

Coping

Participants were at varying stages in their recovery, furthermore, it was evident there were similarities and differences in the coping processes and strategies used to by each individual. All participants had experienced loss as a result of the injury. Coping was seen in several different areas of life, for example coping with the injury to coping with symptoms of the STSG. Coping involved moving beyond the injury or illness and gaining a new perspective on life. The related coping sub-themes that emerged as important to this group of participants included social support, time, and it could have been worse.

Social support.

Several of the participants discussed the importance of the social support they received during their recovery. They spoke about how this support offered assistance with practical issues of daily living and psychological support by means of a distraction. One participant said she had benefited from moving in with her family and taking care of her grandson:

> I stayed in hospital for seven weeks and then was released as an outpatient and then came here because my daughter and my son-in-law lived here so I stayed with them for my recovery and then started going to the Outpatient Burn Centre after that… looking after my grandson has been a very therapeutic, very good thing for me. (Jane)

It is important for survivors to have support to aid in the recovery process, as one participant acknowledged his support network:

> My wife was there as a mentor, my four kids and five grandkids, and neighbours and colleagues from work. So, I think that all played a huge part in, I think, a pretty speedy recovery overall, considering the nature of my burns. (James)

Likewise, Ian described being at home helped reduce the pain and requirement for analgesia: "Here [in hospital] I was just lying in bed and all I could think about was my hands, but when I got home I had my dog and my wife around…it takes your mind off it [pain]".

Traumatic injuries such as burns can have an affect on the entire family. One participant became teary when recalling the accident and stated "I didn't know what was going on...so it was more terrifying for my family" (Judy). For one participant, the injury occurred on a family camping trip. The participant and his grandson were injured badly following a propane explosion. It was evident they were all healing together. He talked about how they were all affected by the accident and he spoke about attending the Burn Survivor's Support Group as a family. A few other participants made mention of the support group available to burn survivors. The group, lead by a burn survivor from 13 years ago, meets monthly to talk informally about their experiences of recovering from a burn injury. One participant described that attending meetings helped frame his expectations on what the burns and grafted areas may eventually look like:

> I didn't know what to expect and it wasn't until I came to a few burn survivor meetings where I got to see a couple of girls that were burned, like, 4 or 5 years ago, to kind of see how it's going to look. (James)

Many of the burn survivors that attend this group go on to provide formal or informal support to other burn patients who are in hospital or struggling with life after the burn injury.

Lastly, participants talked about how support from health care professionals was important to aid in coping with the initial injury. Several of the patients had burned their hands, one participant talked about having to rely on health care staff to assist with activities that were previously taken for granted, for example, feeding himself or help with toileting. As Chris recalled: "I remember I needed to drink some water and I needed to call a nurse to help me". Similarly Judy shared" "that's a big difference…being able to do things for yourself and for a while not being able to". These limitations put the patients in a vulnerable position. The support and encouragement from all members of the health care team are important in the patient's coping process and ability to adapt to their life after a traumatic injury.

Time.

The concept of time seemed to play a role in the participants' ability to adapt to the changes the injury brought, including STSG symptoms and the changes in appearance. Participants described how the STSG grafts had changed over time. For many participants improvements were noted in some areas, while others remained a concern. For example, "I think they have improved with the color and that's about it. How they get tight again, I don't know if that will ever change, but it hasn't so far" (Cindy). Another participant shared: "it's gotten easier over time. I have learned how to deal with it. When people are looking, I just brush it off or just go tell them straight up hat happened…" (Ian).

For a few of the participants, it appears not enough time has passed to accept the losses that have taken place. For example, one participant was able to return to his previous work, however, with modified duties. He goes on to state "I've been there for 7 years. I was

comfortable and, you know, for me to go back to that comfort level is probably never going to be there now" (John). Another participant was unable to return to work, however, the Worker's Compensation Board is funding education that will enable him to re-enter the workforce with a different set of skills. A different participant highlights the time it took to adjust to the injury:

> I tried to just push it away kind of – I didn't come to terms with it – well, I would say maybe even as short a time as six months ago where I finally could just say to myself – well, this is the way it is. And up until that time, it was like – why me? I just want my old life back. And just not really – feeling very uncomfortable and very – like, I remember for the longest time I had a knot in my stomach. It was just always there and I had a hard time sitting still and I had a hard time – relaxation was just not a term that I even thought about. I had to just keep on going. I think that was what it was. I just wanted to keep on going, just so that I could – just thinking I've got to get better and I've got to, you know, I want everything healed and I just want to get on with my life. I just want to get on with my life (Jane).

This is a powerful account for what it was truly like to adjust to life, and that it takes time to heal.

It could have been worse.

It could have been worse was a recurrent theme discussed by several participants. Many of the participants were grateful to have the outcomes they did. One participant spoke about how the injury itself could have been worse "if I was missing a finger or two or something, then my outlook would be totally different" (Ian), therefore, focusing on what he has enabled him to cope with what he has lost. Similarly, another participant stated: "I'm still me and nothing's changed mentally or physically…because some people have got burns and disabilities…that is pretty hard to cope with and I don't think I have that" (James).

Participating in future clinical trials

The last part of the interview focused on patients' opinions towards stem cells, the risk the participant would be willing to take in order to change his/her STSG, and lastly, the level of

evidence that would be sufficient to participate in a clinical trial. This component of the interview is important, as the project our team is working on is to improve STSG through stem cell research. We need to learn if patients would be willing to participate in a future clinical trial. For the purposes of these interviews, patients were not provided any information or background on stem cell therapies. The goal was to hear naïve responses. Furthermore, the majority of questions elicited "yes", "no", "maybe", or "unsure" responses, with few participants offering justification of his/her response.

The findings of this study demonstrated that all 12 participants would be willing to accept a skin substitute derived from their own cells. To illustrate some of the responses heard included: "since it is coming from myself, I am open to it" (Cindy), "I think I would because that is my body, and I think it's safe, to a degree. You're not getting some other person's human cells then you don't know what could happen" (James), and "if you can use your own skin, of course, that is always the best source" (Judy).

The next three questions explored patients' opinions towards allogeneic cells, which are derived from another human being. When participants were asked if they would be willing to accept cells from a family member, the majority answered yes. However, some participants were selective in which family member they would choose; one participant responded by saying: "maybe from my mom, but from my dad or something, probably not, or a sister, probably not" (Ian), similarly a different participant shared: "I think I would only take it from my brother because we have the exact same DNA I guess, because we have the exact same parents" (Cindy). This statement provided evidence the participant has limited knowledge of transplant biology, because unless the subject's brother was her identical twin, they would not share 100 percent of the same DNA.

When asked about cells derived from a close friend, eight participants answered yes, "it's okay if they are willing" (Sarah). When asked about cells taken from a stranger the willingness to accept dropped to seven. As one participant shared: "that's a little more complicated because it involves other people…I don't know if you would have to match or whatever", she then goes on to share that she has a cousin who had kidney transplants and further shared "I know donors in some instances have to have the same blood type" (Judy).

Interestingly, all but one of the patients were willing to accept stem cells derived from umbilical cord blood of a healthy infant if the therapy became available. One participant stated: "whatever works" (Robert). The participant that did not answer yes shared: "I don't know enough about it to say yes or no either way" (Chris). A few participants had previous knowledge regarding the use of stem cells from these sources in other areas of research, for example cancer.

The responses varied on patients' willingness to accept cells derived from animals, also known as xenogeneic cells. Less than half of participants answered yes, three answered no, and four were unsure. One participant that was agreeable stated: "I am sure animals are here for a reason and maybe we just haven't found out all the reasons why, but that could be a good reason if the skin tissue could be used…" (James). Of those participants willing to accept xenogeneic cells, a few had knowledge and/or a family or friend with a pig heart valve: "Why not we are taking pigs valves, heart valves" (Matthew). Similarly, Patrick stated: "yup, I have a friend with a pig's heart valve". Clearly, if given a choice, patients would prefer autologous stem cells for use in clinical trials.

Participants were also asked what risk they would be willing to take in order to change the STSG. Many were willing to have another surgery: "if it was going to improve something, yeah" (Robert), while some would prefer more conservative means, for example injections

and/or creams. A few participants wanted to be assured the treatment would improve the STSG and not make it worse in order to agree to participate in a clinical trial: "if I was guaranteed that my hands would return back to my skin color or the difference between them was not so…dramatic" (Ian), similarly John stated: "if guaranteed that it [treatment/therapy] would make it [STSG] look better, then sure"… if a higher percentage than 50 percent, than I would do it". The majority of participants wanted to know that the cell source is safe and furthermore, several participants talked about not waiting to be the "guinea pig", or first test subject if the therapy became available. "I won't try it out first, maybe a couple of years into it" (Ian).

Lastly, participants were asked what level of evidence would be sufficient to try a novel therapy. For example, if success was achieved consistently in rodents would there be a need to test the therapy in large animals. The participants spoke about the trust they had in the experts: "I would have to trust I guess the medical people to know what they were doing and that I wouldn't be in danger" (Judy). For many the idea that this therapy could one day be available was exciting. A few participants talked about the therapies in terms of helping others, so they would not have to go through what they did: "if it [treatment/therapy] will help other people in the future, I'm with trying it" (Chris). However, not all participants felt the need to improve their STSG:

> Maybe much, much earlier in the process. If they had been assessed after a month that these were going to be a problem and it was going to take another 6-8 months for them to close up completely, I would have taken the risk at that point. But now, no (Patrick).

Summary of Findings

This chapter provides a perspective of what it is like to live with a STSG as identified by 12 unique individuals with STSG varying in size and location. The significant themes for these participants were a new normal, the physical symptoms of STSG, the appearance of new skin,

coping, and participating in future clinical trials. The themes have unique differences yet all related to one another as the individual adjusts to a somewhat different life.

Participants were asked to recollect their expectations prior to receiving a STSG, for the majority of the participants, they described the time leading up to surgery as a blur. Several patients had no recollection because they were sedated in the intensive care unit or "out of it" due to the pain medications, rendering them unable to comprehend the pre-surgical discussions. Moreover, patients expressed trust in the physicians to make the best decision for their best interest: "I relied on their knowledge to heal me the best they could and as quickly as they could and I think that happened" (James). Because of this, whenever possible, it is very important that appropriate discussions and preparation be taken prior to the dressings being exposed.

These findings answer the overall research aim of the study of "what is it like to live with a STSG?" by providing personal, experienced based insights from in-depth conversations with 12 individuals who were able to articulate the reality of living with STSG. While the interpretive themes are unique to the participants of this study and were conceptualized by me, the Principal Investigator, with input from my supervisors, they do verify our anecdotal experience, that patients do have concerns about their STSG, and furthermore provide insight that participants would like to improve their STSG through use of stem cell therapies. The findings have meaningful implications for nurses, physicians, therapists, researchers, and educators that care for patients with STSG. These implications are addressed in the next chapter.

Chapter Five: Discussion & Conclusions

The aim of this research was to describe the experiences of those living with a STSG. It is known from clinical experience that patients have concerns about their STSG, however, there is little literature describing this. In this concluding chapter I provide an interpretation and discussion of the identified themes and their sub-themes from patient interviews, using support from relevant literature, the interview transcripts, and my reflective journal. I will also present potential implications for practice from knowledge gained. I will discuss the limitations of this study, how rigor and trustworthiness were maintained, followed by an account of my experience as novice researcher stepping out of my role as a nurse, and furthermore, what this research can add to the advanced nursing practice role. Lastly, I present implications for future research.

According to Thorne (2008) "nursing always and inherently requires knowledge about patterns and themes within people in general so that it can better inform the care of the unique and distinct individual" (p. 25). The main overarching theme in this study was a new normal. This theme was heard throughout three of the four interpretive themes identified: a) physical symptoms of STSG; b) appearance of new skin, d) coping; and e) participating in future clinical trials.

Synthesis of interpretive themes and related literature

A new normal.

Adapting to a new normal was the overarching theme found in this research and was described in three of the themes and the eight of the subthemes. All participants talked about adjusting to the outcomes of the injury and STSG during the interviews. Adjustment has been defined as "the acquisition of modifications in an individual that enable him/her to adjust to life

in a new environment" (medical dictionary, 2012). Patients in this study went through a process of learning how to live with their new skin, new appearance, and changed life circumstances.

Time played a role in the participants' ability to adapt to the changes the injury brings, including STSG symptoms and changes in appearance. Although the stages of recovery are beyond the scope of this research, many participants described the passage of time as an important part of their recovery. With the passage of time, many participants reported improvements in their wounds, function, and the ability to return to previous work and leisure activities. Whether participants wanted to improve or change aspects of their "new selves" was dependent on many factors. Dahl, Wickman, and Wengstrom (2012) report similar findings in a recent qualitative study. Through semi-structured interviews with 12 participants, they found participants' experiences following burn trauma and hospitalization were life changing and altered the participants' perspectives of life: "the body skin feels different in the burned areas: thicker and plastic without distinct sensitivity. Daily activities such as taking a shower and getting dressed have to be planned more carefully"… (p. 5). The majority of participants in Dahl, Wickman, and Wengstrom's study had gained a new understanding of life (p. 601), thus learned to adapt to a new normal, which was congruent with my study. Dahl's study looked at adaptation following a burn injury in general terms, whereas my study explored at experiences specific to patients requiring a STSG. Inherent in this 'new normal' was a process of adaption, which is illuminated by the range of physical symptoms they experienced following STSG surgery. Therefore, my study showed similarities with Dahl's findings, but also offers new knowledge and insights for patients living with STSG.

The participants reported that they did not have a good understanding of what to expect from their skin grafts. One implication for practice is that clinical teams caring for patients

requiring STSG should consider an appropriate educational plan for both patient and caregivers that includes the pre- and post-operative phases of recovery prior to the initial post-operative dressing take down. It is possible that we could reduce the psychological impact of the pain and appearance of the skin graft and donor site by better preparing our patients and their caregivers for the outcomes that we consider acceptable at different stages of healing and evolution of the skin graft.

Physical symptoms of STSG.

The participants of this study identified four main symptoms or sub-themes that are problematic in their day-to-day lives. These sub-themes were a) itch and dryness; b) pain; c) altered sensation; and d) function of STSG. Some of these symptoms have been identified in other scar scales, for example the patient and observer scar scale (POSAS) (Draaijers, 2004), which is a tool that has patients rate a variety of symptoms on a 10 point Likert scale. Although this scale helps the observer, usually a therapist or physician assessor, gain an appreciation of the symptoms patients are experiencing, the scale provides little insight into how patients live with the symptoms. Findings also show the inter-rater reliability of the POSAS is poor (Draaijers, et al., 2004) which limits the use as the same observer is not always present at each patient follow-up. My study has allowed us to hear from patients not only what the most concerning STSG symptoms were, but also how patients live and cope with the symptoms on a daily basis. All of the symptoms described are due to the fact that the patients with STSG no longer have a normal dermis. As described earlier, the dermis provides maintenance to the overall structure and function of skin by means of supporting nerves and blood vessels, regulating hair follicles, sebaceous glands that lubricate the skin, and sweat glands, which are important in thermoregulation (Crandall & Davis, 2010). Furthermore, normal dermis contains significant

extracellular matrix that accounts for the tensile strength and elasticity of the dermis (Sherwood, 2004).

All participants reported at least one physical symptom related to their skin graft. Although these participants were selected from patients still receiving care through a burn clinic at a university based burn center, they were at least two months to more than two years from their surgical procedure. Although STSG is sufficient to close the physical wounds, these patients are left with chronic impairments in skin function.

Itchiness and Dryness.

Itch and dryness of skin was often a pernicious and persistent feature following STSG for patients in this study. Itch, also known as pruritus, is a common and distressing symptom patients report post burn injury (Bell & Gabriel, 2009). It has been defined as a persistent desire to scratch (Zachariah, et al., 2011), and can occur in burns that heal with or without STSG (Wiechman, 2011). Such symptoms can have far reaching affects on the patients' sleep and quality of life (Bell & Gabriel, 2009). The risk of relieving the itch, for example, through scratching can cause further problems with the STSG by causing a break in the skin (Wiechman, 2011). Although research has shown that post burn pruritus tends to decline after the first year following the injury (Ahee, Smith, Pliska-Matyshak, et al., 1999), the majority of participants in this study experiencing itch, were beyond a year of his/her injury and STSG surgeries. Several participants experienced itchiness in conjunction with dryness. These individuals often had relief from both symptoms with the application of a moisturizer. Itch in the absence of dryness was reported in my study and required pharmacological treatment. The nurse's role in the acute phase, and proliferative phase of wound healing, is to treat the itch as it occurs. The primary approaches are daily cleaning and application of moisturizer, and if required, the use of

pharmacologic agents such as antihistamines. During the rehabilitative phase, which includes the wound remodelling phase and beyond, patients need to report when itch becomes problematic so the physician can prescribe appropriate therapies to relieve itch and moreover prevent an open wound from forming.

Pain.

All but one of the participants in this study described pain that occurred at some point from the injury to the time at which the interview took place. The International Association for the Study of Pain (IASP) defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (IASP, 2011). Accordingly, each participant's pain was unique and did not seem to be related to the size of the STSG. Patients' described the donor site pain from the STSG surgery to be a significant source of pain. Although there have been improvements in STSG techniques, the procedure remains an additional source of pain for patients (Connor-Ballard, 2009). Patterson, Hoflund, Espey, and Sharar (2004) found that post-operative pain following excision and grafting required increased analgesia for 1-4 days following surgery. The source of pain for patients in Patterson et al.'s (2004) sample was mainly related to donor site pain rather than the grafted area. My participants also remembered the five day dressing removal to be a painful experience. This caused further anxiety and fear for subsequent dressing changes. Nurses performing dressing changes need to ensure that the patient's pain is well controlled in the acute phase. Research suggests poor pain management in the acute phase can lead to long-term chronic pain (Richardson & Mustard, 2009). There is also evidence to suggest that nurses and physicians do a poor job assessing and managing pain in clinical practice (Yuxiang et al., 2012). Clinicians need to regularly assess and treat pain to ensure patients do not suffer during any phase of the injury and recovery process. Furthermore,

there is need for further education during training with ongoing learning opportunities to keep current and competent in the area of pain management.

Although it is unrealistic to be pain free, nurses have an important role in assisting patients to set realistic pain goals, while also offering and using a variety of approaches to treat pain in the acute phase of the patient's injury. We also need to utilize the multi-disciplinary team more effectively when it comes to pain management. One of my participants attested to the value of being offered and using guided imagery as an adjunct to her medication regime. Guided imagery and/or hypnosis in addition to pain medication have shown effectiveness in the burn population (Berger, et al., 2010). Nurses, psychologists, social workers, and/or rehabilitation therapists can provide and teach complementary therapies. Again, ongoing training to maintain current in the area of pain management is essential. A psychiatry consult may also be appropriate if the patient is experiencing underlying anxiety and/or depression (Esfamlan, Lotfi, Zamanzadeh, & Betapuor, 2010). Nurses trained in burn care should also have the clinical competency of assisting with conscious sedation, a pain management technique that is often overlooked, and could benefit many patients at the time of his/her 5 day dressing removal. In my experience, a significant barrier to providing conscious sedation is the ability to get an anaesthetist to perform the procedure. This may be due to lack of available resources and/or lack of understanding in the area of burn pain. Communication amongst the multi-disciplinary team and advocating for the patient are essential in providing effective pain management.

None of the participants spoke about pain persisting much beyond their hospitalization. A few participants did take narcotic pain medication upon discharge however, none of the patients continued to experience pain that required opioid analgesia at the time of the interview. This is not always the case for patients who have been discharged home; many do go on to

experience pain that requires long-term treatment and if not treated can lead to sleep disturbances, ability to work, and decrease overall QoL (Summer, Puntillo, Miaskowski, Green, & Levine, 2012).

Altered Sensation.

Many of the participants in this study experienced hypersensitivity, numbness, or both sensations within the STSG. For those experiencing hypersensitivity, desensitization was a common strategy used in therapy sessions. For some patients the hypersensitivity required pharmacological management. For patients experiencing numbness or lack of sensation to the STSG, an increased awareness of the environment became important, for example checking water temperature with an area of the body with normal temperature perception. None of the participants talked about repeat injury, however, the risk is increased and may require individuals to seek medical attention if the STSG is injured as a result of the altered sensation. Sensation can take months to years to stabilize and innervation will always be incomplete with some degree of permanent derangement (Wax, Pittman, & Ghanem, 2013). Health care providers must therefore stress to patients the importance of having an increased awareness of their body to help prevent injury to the STSG, for example, by performing daily skin checks.

Function of the STSG.

In this study, participants talked about the fragility of their STSG, which for some had resulted in the graft shearing, leading to an open chronic wound. Others described frustrations with decreased elasticity of the STSG. They talked about the amount of time stretching took and how quickly gains in movement were lost if they decided not to stretch. Decreased elasticity was seen as a severe flexion contracture in one participant that required surgical intervention. The function of the STSG is important for returning to work and activities of daily living. Due to the

heterogeneity of the outcomes from STSG, some areas may be thicker, which can in turn affect the elasticity of the scar; other areas may be thinner which affect the physical integrity making the once healed STSG fragile and prone to break down and open wounds (Wax, Pittman, & Ghanem, 2013). A few participants in this study, two which were beyond a year of STSG, were still experiencing open wounds that required ongoing medical care. When the wound is open, the patient is at an increased risk of infection.

When the graft is initially placed, the risk of graft loss is increased for several days following the surgery. The surgeons who perform the procedure work hard to provide a protective dressing and splinting if required. Nurses must stress the importance of keeping the grafted area immobilized and the underlying reasons for this, which in my centre requires bedrest and/or strict immobilization of the grafted area until post operative day five when the dressing is removed for assessment of the STSG. Despite meticulous care and preventative measures, some patients experience a STSG that becomes chronically open and does not heal. The required treatment may be further debridement and STSG, which also means another donor site. If the open areas are small, the patient will be treated conservatively with regular dressing changes.

It is important that nurses properly splint and position patients according to physician and therapists directions in order to maximize the patients' chances of optimal functional recovery of the STSG (Chan, Barzi, Harvey, & Holland, 2013). It is also essential that patients participate in their therapy sessions to increase range of motion and decrease the risk of contractures. Physiotherapy can be painful and time consuming but its importance cannot be stressed enough. Therapists are good at promoting proper splinting and positioning, however, two problems that commonly arise are the patient is non adherent and refuses the directions and splinting schedules, and/or the nurses do not understand the importance of splinting in the acute phase to prevent

long-term problems. It would be interesting to study the reasons why patients do manage wearing their splints, and nurses' understanding of the purposes of proper positioning and splinting.

In order to decrease the occurrence of open wounds and risk of infection, patients need education on how to properly care for the STSG and how to care for open wounds, including signs and symptoms of infection. Nurses can teach patients to avoid activities that increase the risk of breakdown, however, when the STSG takes up a large percentage of the patient's total body surface area or a functional region such as the hand, it can be impossible to prevent all trauma to the skin. Furthermore, the current reality of living with a STSG is the grafted skin will never be mechanically normal.

Appearance of new skin.

Participants in this study frequently made reference to the appearance of their scars and were comfortable showing me to help tell their stories. This may be because many of the participants knew me from my role as a nurse on the burn unit and were aware I had seen many different kinds of scars. Nurses are usually the first providers who are with patients when they see their scars. It is important that we properly prepare patients for what they can expect to see.

How do people with scars live comfortably within a western culture which places high value on physical beauty and perfection? As with pain, appearance is a phenomenon that is influenced by many factors including an individual's body image, self esteem, coping mechanisms, (Thombs, Notes, Lawrence, Magyar-Russell, Bresnick, & Fauerbach, 2008). For some individuals a small pimple can cause huge anxiety, while those with a large, disfiguring burns may cope well (Sainsbury, 2008). Findings suggest that anatomical location does not necessarily predict how well patients are able to cope (Sainsbury, 2008). While other findings

show that visible scarring may be associated with greater distress (Lawrence et al., 2004). This research found a combination. Many patients described how they were satisfied with the appearance of the STSG, but admitted if the scar was in a visible location the outcome may be more difficult to accept. The patients who did have visible scars had different ways of covering them up, for example with a scarf or compression garment.

Addressing appearance of the STSG scars requires a multi-disciplinary approach. Physicians should educate patients on what to expect in the long-term and provide follow up for possible reconstructive options. Nurses can offer patients tools that can assist with responding to others who ask about the scars. Therapists can provide treatment modalities that potentially limit scars, and psychologists can assist patients through various techniques individualized to the patients needs.

Coping.

Coping was a theme that arose in all of the interviews. Participants in this study described ways of coping with their injury and resulting STSG in various ways. Coping is a concept that was described during the 1960s and 1970s as interest was gained in the area of psychological stress research (Lazarus, 1993). In its simplest terms, coping is defined as an "ongoing cognitive and behavioral effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." (Lazarus, 1993, p. 237). Acceptance has been found to be a positive coping strategy and is related to adaptation (Bernstein, O'Connell, & Chedekel, 1992).

For many participants social support from family, friends, and the availability of the burn support group were mentioned as key in moving beyond the injury. Several participants also acknowledged the unit staff as being a motivating factor in the recovery process. The burn team

plays a large role in ensuring adequate support is available in order to assist patients in their recovery (Moi, Vindenes, Gjengedal, 2008). Recently, in our centre, this included identifying the added value of patients' families and friends in the recovery process. This required changes in unit guidelines, including more flexible visiting hours, increased participation in care from families, and a greater focus on improving the patient/family experience by providing more information and resources to cope with the injury. Some survivors go on to receive formal training through the Phoenix Society. The training is called Survivors Offering Assistance in Recovery, or SOAR. In order to be a SOAR trained peer supporter, survivors meet certain criteria and go through a screening process to ensure they are appropriate to provide support (Phoenix Society, 2007). This can provide an invaluable opportunity to support others who have endured the trauma of burns and strengthen their own sense of coping. The peer supporter provides the patient with an opportunity to share his/her fears and to see someone who has adapted to life after their injury. It is the burn team's responsibility to ask the patient if they would like to speak to another survivor, and then choose the most appropriate survivor for that patient. For example, if the patient had required amputations, the peer supporter chosen would also be an amputee.

As participants move from victim to survivor, they often find ways to cope with the limitations they may face. Whether the end result is adaptation to the injury often depends on the coping style and process (Rosenbach & Renneberg, 2008). Essentially, they must put the "old normal" behind them and learn to live with a "new normal" which may require changes to previous work, different or modified leisure activities, and changes in relationships.

Participating in future clinical trials.

Understanding patients' views on acceptability of stem cell therapy was an important component of this research, as I was interested if patients that had STSG would be willing to accept stem cells that could potentially improve the characteristics and unwanted symptoms of the STSG. When given a choice between autologous (from the individual's body), allogeneic (from another human's body), xenogeneic (from an animal) and other stem cell sources, patients preferred autologous stem cells; in fact all participants were open to the option. Clover et al. (2012) found similar results with over 92 percent of people attending plastic surgery/burns outpatient and medical outpatient clinics with acute burns, burn reconstruction, diabetes, and Parkinson's disease were willing to accept autologous cells. Participants likely believe this is the safest option for stem cell therapy, as they would be using cells derived from themselves.

In this study, the majority of participants would also be willing to accept stem cells from other humans. One of the main reasons I suspect patients would agree to accepting allogeneic cells was patients are aware the vast majority of blood transfusions are from donors, and it was possible several of the patients in this study had blood transfusions (Finucane, Slovic, Mertz, 2000). Secondly, not all patients were likely aware of tissue and/or organ rejection and the need for immunosuppression if allogeneic solid tissue sources are transplanted, again, this may be attributed to the fact that blood transfusion does not require immunosuppression. A few participants did have knowledge about immunosuppression; despite this they were still willing to accept allogeneic cells.

It is unclear from this research why the participants would agree to stem cells derived from umbilical cord blood. Perhaps some patients had previous knowledge of the use of this stem cell source in the treatment of certain cancers, for example leukemia (Barker & Wagner, 2003).

Another possibility is cord blood has gained more attention in the media; the request for cord blood donation can be seen on television and is advertised in obstetric clinics. Similarly, participants may not understand the implications of the cell source.

This study found that a few patients were willing to accept cells from an animal. Similarly, Omnell Persson, et al. (2003) found patients were positive to transplantation of xenogeneic cells, which is interesting because "transplantation with heart valves is a well-established method…prepared in such a way that infectious agents will be destroyed. The technique of transplanting xenogeneic cells is new and the risk has not been fully evaluated" (p.76). Therefore, although a portion of the pig's organ has an established clinical application, this does not include the cells themselves. Having knowledge that animal organs are used in humans, and for some participants in this study, in family and friends, likely influenced a few of the participants' responses in this study.

Patients' decision on what risk they were willing to take to improve his/her STSG was found to be influenced by several factors, including where they were with overall coping with the injury, new skin, and recovery. For some patients, the thought of going through another surgery and being set back after coming so far was not appealing. For others, surgery was a viable choice if there was some degree of certainty of improved STSG symptom outcome. A minimally invasive technology such as an injection would likely be more acceptable as several of the participants did not want to go through another surgery.

The readiness for patients to experiment with a new treatment is likely related to each individual's severity of STSG symptoms and his/her level of acceptance with the scars from the STSG. If I were suffering from constant stiffness and open wounds, I believe I would be willing to try a stem cell therapy if it were available. However, as a few participants mentioned, they

would have to be faced with the option and provided with informed consent. One of the drawbacks of a new therapy is the time required to translate bench science to human clinical trials (Kwon, Ghag, Reichl, Dvorak, Illes, and Tetzlaff, 2012). If there were a high degree of certainty with mouse model, would it be realistic to move straight to humans rather than following the "usual" progression to a pig model prior to human trials? This question too is likely related to how desperately patients want to try a treatment that could potentially improve their STSG. Although this therapy is not yet available, in a potential future situation, the nurse's role would be to provide teaching and reinforce information provided by the physician team. Therefore, nurses would also require a thorough understanding of the application of stem cell therapy for STSG.

Limitations

This section combines a discussion of the limitations and concerns around methodological rigour related to this study. This research had a number of limitations. Although recruitment and obtaining consent for participation was not problematic; at times it was difficult finding an agreeable and convenient time to conduct the interviews. For a few interviews the patients consented, and preferred that the interview took place immediately. These instances did not allow much preparation for me, the researcher; and required I was always prepared to conduct an interview at a moment's notice. I always ensured I had my interview tool, journal, recording device, and private room readily available. Nonetheless, the quality of the interview may have been threatened in these cases. I did learn how to be flexible, but always found the interviews that were done with more planning were slightly more relaxed. The planned interviews tended to take more time, as the patients did not seem to be in a rush. Furthermore, I

do believe I may have obtained richer data in these circumstances. However, I quickly learned if I was not flexible with the interview schedule, I might miss out on the opportunity.

The time in months post STSG varied from 2-29 months. The inclusion criteria could have included patients with a specified length of time post STSG. Regardless, all patients did describe symptoms that are a result of the STSG. Similarly, I did not separate out patients who had received a meshed STSG versus a sheet STSG. A meshed graft is more prone to contraction due to the fact that the graft must heal in between the expansion by epithelization and at times may retain the meshed appearance. Therefore, I was unable to determine from this research if patients that had a meshed graft versus a sheet graft reported more problems related to the STSG.

Due to the fact that participants were from a single centre, anonymity and confidentiality were difficult when presenting findings. Participants were assigned a pseudonym, however, they still may be able to self identify. Another limitation was one of the participants spoke English as a second language and was quite soft spoken. When going back to the data, her voice was difficult to hear on the recording device, thus posed challenges for transcription. Therefore, the inclusion criteria should read fluent in English, rather than English speaking.

Lastly, it may be argued that the stem cell questions were rather quantitative in nature and do not align with the interpretive description methodology. However, Thorne (2008) stated that the goal of interpretive description is to have a direct impact on practice. This research does inform further research through discovering the most problematic issues for these patients living with STSG, and furthermore, through the stem cell questions, what patient's opinions are towards receiving stem cells from various cell sources as this research is underway.

As mentioned in chapter three, rigour and trustworthiness are important to maintain throughout the research process. In qualitative research, the criteria for rigour and

trustworthiness include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1981). Rigor in qualitative research is often difficult to assess and demonstrate, however, I believe I was transparent through the research process by providing a clear audit trail, including a thick description through the use of direct quotations of participants. (see appendices for a coded transcript). Transparency addresses the dependability criterion. Although this study is limited as it only investigated patients' experience with STSG in one burn centre, the findings may provide resonance to other patients living with STSG; thus, transferability is captured in this study. Credibility is enhanced through the use of reflexivity, which I describe in detail in the next section. Another essential credibility consideration is the need for disciplinary relevance when generating knowledge from interpretive description (Thorne, 2001), thus asking whether the knowledge is appropriate. I believe this has been emphasized throughout the research process and captures the confirmability criteria that Lincoln and Guba describe. There is a gap in the literature that describes scarring as a result of STSG, and this research provides insight into this phenomenon.

Reflexivity

Taking on the role of researcher was a challenge for me, and I would like to discuss the tensions that arose during this study, and furthermore, what I have learned that I will take with me into my future as a nurse researcher. This awareness is referred to reflexivity and is critical in nursing research where the participants are known to the researcher (Jootun & McGhee, 2009). Reflexivity also enhances the quality of research through understanding how one's own values and views may influence findings (Jootun & McGhee, 2009). As Thorne (2008) stated: "despite being drawn to qualitative research because of their enthusiasm for subjective experiential clinical knowledge, many clinicians find the transition into the role of researcher considerably

more difficult than they had first imagined" (p. 108). This quote captures my experience exactly. Similarly, Bailey (2007) put forth two valid questions I too asked myself: "as a researcher, when do I stop being a nurse? Or, in all honestly, as a clinical researcher, do I ever stop being a nurse?" (p. 23). At times I struggled with the boundary between my role as a clinical nurse and a nurse researcher. Working as a nurse in the practice setting, the majority of the participants in my study knew me, either from my current role as the clinical nurse educator in the unit, my previous role as a beside nurse, from my time in clinic, or from my involvement in the burn survivor group. This likely meant they trusted me and felt comfortable asking me questions. During some interviews I was asked question about the STSG or related aspect and would naturally respond by providing some teaching/education, which was not the intent of the interview. Therefore, to answer the above questions, I would say no, one does not ever stop being a nurse, however, we learn to assume different nurse roles at different times, an ability which takes time and practice. As a novice researcher I have learned from this research experience and have gained an awareness of the skill required in being able to refer the patient to others in a similar situation or defer the question for another time. Similarly, Thorne (2008) emphasizes how a clinical interview varies greatly from a research interview, and clinician's tendency to "lead the witness" (p. 110), is a skill that can take considerable time undoing. I certainly became aware of this early on in the research. Upon reviewing interview transcripts, I discovered I would answer for participants or ask several questions at once, which meant I did not always get an answer to all of the questions. I did not always see my weaknesses at the outset of the interviews; my identified researcher inadequacies were learned during data analysis. I believe this awareness will be improved in future research I plan to pursue.

Lastly, my role as a clinician is also unique in that I work within the larger skin research team where the focus is on basic science, and thus research is always quantitative and inherently positioned within the positivist paradigm. This required me to bridge the gap between the philosophical paradigms embedded in qualitative and quantitative research, and find a middle ground to ensure I stayed true to my professional goals, the aim of the study, and chosen methodology. It may however, also have influenced the way in which I interpreted the data. For example, when I began to analyze the data, I was inclined to count responses and look for correlations. With the help of my supervisory committee I was able to refocus on the words and actions of participants to obtain a thick description of the data gathered.

Advanced Nursing Practice

The purpose of this research was two fold. The first was to conduct a sound research study to obtain knowledge in an area where a gap in research existed so there may be contributions to the field. I believe this study does add a new understanding of what it is like to live with STSG to the current literature. Furthermore, findings from this study have direct nursing practice implications. Knowing that patients experience a new normal following STSG, nurses have a pivotal role in providing education in all phases of recovery, including how to care for the STSG, how to interact with others in difficult situations, what to expect in the long term, and with support from physicians, possible treatment options that may improve the STSG characteristics that may be problematic and worrisome.

The second purpose was to obtain a Master of Nursing (MN) degree so I may be better equipped to function in the role of an advanced practice nurse. The Canadian Nurses Association stated the guidelines for key competencies for advanced nursing practice are grouped into five main areas; clinical competencies, research, leadership, consultation and collaboration (Canadian

Nurses Association, 2008). Completing the requirements of a MN thesis will provide me with the tools required to work as an advanced practice nurse and fulfill the above clinical competencies. These new understandings of living with STSG will impact my clinical practice and improve the education I provide to staff, the care I provide to patients and provide a basis for further research I hope to pursue. I believe many of the implications of this knowledge were shared throughout this chapter and will be built on in future research that is currently underway.

Research Implications

There is a dearth of qualitative research exploring the patients' experience of STSG. This study allowed me to look at my patients through a new lens and gain a deeper appreciation of what it is like to live with a STSG. Patients not only talked about their experiences living with a STSG, but also what it is like to live through a burn injury. In future studies it would be beneficial to separate the experiences of living with a burn injury versus living with a STSG.

According to Thorne (2008) the interpretive description is not complete until the mention of future research has taken place. I am fortunate to work within a team where the aim is to improve STSG through the use of stem cells (Biernaskie & Gabriel, 2012). This study provides a foundation from which a similar future study will take place within a programme of research, which spans basic science at the bench to clinical practice. Thorne (2008) also refers to the importance of providing useful recommendations from the study conducted and proposes recommendations for further research include advantages of how other methods may contribute to the phenomenon of interest. The limitations from this study have been addressed and the next interviews will take place using a refined interview tool to capture areas that require further insight and investigation. The next phase of the research will follow a mixed methods design incorporating both qualitative and quantitative elements. Furthermore, because the research

team's plan is to eventually carry out a clinical trial, we want to know about the clinical priorities not only of patients with STSG, but also people at risk for STSG (firefighters), and those performing STSG (surgeons) so we can design the most appropriate outcome measures. In future studies we will also be considering what patient demographic and psychological factors are associated with a specific expectation or acceptance of risk. In the future study, patients will be invited to participate in an interview prior to their STSG to determine expectations pre-surgery. They will also complete several questionnaires including a personality inventory of pain, a post-traumatic stress disorder screen, a depression screen, a scale of perceived social support, and the standard gamble. These tools were selected as representative of common disorders present in patients with burn injuries and that may influence participating in a future dermal stem cell clinical trial (Thombs, Bresnick, & Magyar-Russell, 2006). Furthermore, this research has potential to impact other areas, for example cancer patients experiencing alopecia as a result of chemotherapy, through the ability to improve dermis through the use of stem cells.

Conclusion

This is a novel research study that explored what it is like for patients to live with STSG, an unexplored area in the literature. This study confirmed many of my preconceived notions of what it is like to live with STSG, including the unpleasant side effects patients are living with, but also provided several new, in-depth understanding of the participants' experiences. I had an idea of the impact the unpleasant symptoms of STSG had on patients' lives, but did not grasp the extent symptoms such as altered sensation and decreased elasticity had on QoL. The themes that were identified in the data included a new normal, physical symptoms of STSG, appearance of new skin, coping, and participating in future clinical trials. Each participant had a unique experience of living through his/her injury, living with a STSG, and perhaps most importantly

living life in a new or modified way- *a new normal*. The findings revealed that all participants in this study would prefer autologous stem cells to improve his/her STSG. These findings provide a basis upon which nurses and other health care professionals will treat patients that have had STSG. This study also provides a starting point for further research in the area of STSG as we now know that the scars as a result STSG are problematic for patients and discovered that patients are motivated to try therapies that could potentially improve the outcomes of their STSG. In my role as a nurse working with the patient population studied, I have gained a deeper appreciation for the unpleasant and long-term outcomes of patients living with STSG.

References

Abdullah, A., Blakeney, P., Hunt, R., Broemeling, L., Phillips, L, Herndon, N. & Robston, M. C. (1994). Visible scars and self esteem in pediatric patients with burns. *Journal of Burn Care and Rehabilitation, 15*(2), 164-168.

Alexander, H. & Miller, D. (1979). Determining skin thickness with pulsed ultrasound. *Journal of Investigative Dermatology, 72,* 17-19. doi:10.1111/1523-1747.ep12530104

Al-Mousawi, A. M., Rivera, G. A., Jeschke, M. G., & Herndon, D. N. (2010). Burn teams and burn centers: The importance of a comprehensive team approach to burn care. *Clinics in Plastic Surgery, 36*(4), 547-554. Retrieved from https://www-clinicalkey-com.ezproxy.lib.ucalgary.ca/#!/ContentPlayerCtrl/doPlayContent/1-s2.0-S009412980900073X

American Burn Association (2012). National Burn Repository- report of data from 2002-2011. Retrieved http://ameriburn.org/2012NBRAnnualReport.pdf

Anzarut, A., Chen, M., Shankowsky, H., Tredget, E.E. (2005). Quality-of-life and outcome Predictors following massive injury. *Plastic & Reconstructive Surgery, 116*(3), 791-797. doi: 10.1097/01.prs.0000176257.22583.46

Barrow, R. E. & Herndon, D. N. (2007). History and treatment of burns. In Herndon, D. N. (Ed.). *Total Burn Care* (3rd ed.) (pp. 1-8). Philadelphia, PA: Elsevier.

Bailey, C. J. (2007). Practitioner to researcher: Reflections on the journey. *Nurse Researcher, 14*(4), 18-26.

Barker, J. N. & Wagner, J. E. (2003). Umbilical cord blood transplanation for the treatment of cancer. *Nature Reviews Cancer, 3,* 526-532. doi:10.1038/nrc1125

Bell, P. L. & Gabriel, V. (2009). Evidence based review for the treatment of post burn pruritus.

Journal of Burn Care & Research, 30(1), 55-61. doi: 10.1097/BCR.0b013e318191fd95.

Berger, M. M., Davadant, M., Marin, C., Wasserfallen, J. B., Pinget, C., Maravic, P., Koch, N., Raffoul, W., & Chiolero, R. L. (2010). Impact of a pain protocol including hypnosis including hypnosis in major burns. *Burns, 36,* 639-646. doi: 10.1016/j.burns.2009.08.009

Bernstein, N. R., O'Connell, K., & Chedekel, D. (1992). Patterns of burn adjustment. *Journal of Burn Care & Rehabilitation, 13*(1), 4-12.

Bethedsa (2012). What are adult stem cells? National Institutes of Health. Retrieved from http://stemcells.nih.gov/info/basics/pages/basics4.aspx

Biernaskie, J. & Gabriel, V. (2012). [Autologous adult dermal stem cell transplantation to improve function of split thickness skin grafts]. Unpubished raw data.

Biernaskie, J., Paris, M., Morozova, O., Fagan., M., Perry, L., Miller, F. (2009). SKPs derive from hair follicle precursors and exhibit properties of adult dermal stem cells. *Cell stem cell 5*(6), 610-623. doi:10.1016/j.stem.2009.10.019

Blades, B., Mellis, N., Munster, A. M. (1982). A burn specific health scale. *Journal of Trauma, 22,* 872-875.

Blakeney, P., Rosenberg, L., Rosenberg, M., & Fauerbach, J. A. (2007). Psychosocial recovery Reintegration of patients with burn injuries. In Herndon, D. N. (2007). *Total Burn Care* (3rd ed.). Philadelphia, PA: Elsevier.

Bombaro, K. M., Engrav, L. H., Carrougher, G. J., Wiechman, S. A., Faucher, L., Costa, B. A., Honari, S. (2003). What is the prevalence of hypertrophic scarring following burns? *Burns, 29*(4), 299-302. doi:10.1016/S0305-4179(03)00067-6

Brown, B. C., McKenna, S. P., Siddhi, K., McGrouther, D. A., & Bayat, A. (2008). The hidden cost of skin scars: Quality of life after skin scarring. *Journal of Plastic, Reconstructive &*

Aesthetic Surgery: JPRAS, 61(9), 1049-1058. doi:10.1016/j.bjps.2008.03.020

Brown, B. C., Moss, T. P., McGrouther, D. A., Bayat, A. (2010). Skin scar preconceptions must be challenged: importance of self-perception in skin scarring. *Journal of Plastic, Reconstructive & Aesthetic Surgery, 63, 1022-1029. (Fauerbach et al.)*

Brusselaers, N., Pirayesh, A., Hoeksema, H., Verbelen, J., Blot, S., & Monstrey, S. (2010a). Burn scar assessment: A systematic review of objective scar assessment tools. [Review]. *Burns, 36*(8), 1157-1164. doi:10.1016/j.burns.2010.03.016

Brusselaers, N., Pirayesh, A., Hoeksema, H., Verbelen, J., Blot, S., & Monstrey, S. (2010b). Burn scar assessment: A systematic review of different scar scales. [Review]. *Journal of Surgical Research, 164*(1), e115-123. doi:10.1016/j.jss.2010.05.056

Burd, A., Lam, A. S., Ayyappan, L. T., Huang, L. (2007). Stem cell strategies in burns care. *Burns, 33,* 282-291. doi: 10.1016/j.burns.2006.08.031

Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science, 1*(1), 13-24.

Canadian Nurses Association. (2008). *Advanced nursing practice: A national framework.* Ottawa, ON: CNA. Retrieved from http://www.cna aiic.ca/CNA/documents/pdf/publications/ANP_National_Framework_e.pdf

Clover, A. J. P., Lane O'Neil, B., Kumar, A. H. S. (2012). Analysis of attitudes toward the source of progenitor cells in tissue-engineered products for us in burns compared with other disease states. *Wound Repair and Regeneration, 20*, 311-316. doi: 10.1111/j.1524-475X.2012.00779.x

Connor-Ballard, P.A. (2009). Understanding and managing burn pain: part 1. *American Journal of Nursing, 109*(4), 48-56. doi: 10.1097/01.NAJ.0000348604.47231.68

Chan, Q. E., Barzi, F., Harvey, J. G., & Holland A. J. A. (2013). Functional and cosmetic outcomes of full versus split thickness skin grafts in pediatric palmar surface burns: A prospective, independent evaluation. *Journal of Burn Care & Research, 34*(2), 232-236. doi: 10.1097/BCR.0b013e31826fc53d

Crandall, C. G & Davis, S. L. (2010). Cutaneous vascular and sudomotor responses in human skin grafts. *Journal of Applied Physiology, 109*(5), 1524-1530. doi: 10.1152/japplphysiol.00466.2010.

Dahl, O., Wickman, M. Wengstrom, Y. (2011). Adapting to life after burn injury: Reflections on care. *Journal of Burn Care & Research, 33*(5)*,* 595-605. doi: 10.1097/BCR.0b013e31823d0a11

de Witt, L. & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*(2), 215-229. doi: 10.1111/j.1365-2648.2006.03898.x

Draaijers, L. J., Tempelman, F. R. H., Botman, Y. A. M., Tuinebreijer, W. E., Middelkoop, E., Kreis, R. W., & van Zuijlen, P. P. M. (2004). The patient and observer scar assessment scale: A reliable and feasible tool for scar evaluation. *Plastic & Reconstructive Surgery, 113*(7), 1960-1967. doi: 10.1097/01.PRS.0000122207.28773.56

Druery, M., Brown, T.L.H., & Muller, M. (2005). Long term functional outcomes and quality of life following severe burn injury. *Burns, 31,* 692-695. doi: 10.1016/j.burns.2005.03.001

Du, Y.-C., Lin, C.-M., Chen, Y.-F., Chen, C.-L., & Chen, T. (2006). Implementation of a burn scar assessment system by ultrasound techniques. *Conference Proceedings: ... Annual International Conference of the IEEE Engineering in Medicine & Biology Society, 1*, 2328-2331. doi:10.1109/IEMBS.2006.260018

Egeland, B., More, S., Buchman, & Cederna, P. S. (2008). Management of difficult pediatric facial burns: Reconstruction of burn-related lower eyelid ectropion and perioral contractures. *The Journal of Craniofaical Surgery, 19*(4), 960-969. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/18650718

Elsherbiny, O. E. E., Salem, M. A., El-Sabbagh, A. H., Elhadidy, M. R., Eldeen, S. M. A. (2011). Quality of life of adult patients with severe burns. *Burns, 37*(5), 776-789. doi: 10.1016/j.burns.2010.12.017

Esfamlan, A. J., Lotfi, M., Zamanzadeh, V., & Betapuor, J. (2010). Burn pain and patients' responses. *Burns, 36*(7), 1129-1133. doi: 10.1016/j.burns.2010.02.007

Esselman, P.C. (2007). Burn rehabilitation: An overview. Archives of Physicial Medicine and Rehabilitation*,* 88, S3-6.

Essleman, Ptacek, J. T., Kowalske, K., Cromes, G., de Lateur, B., & Engrav, L. H. (2001). Community integration after burn injuries. *Journal of Burn Care & Rehabilitation, 22*(3), 221-227.

Fauerbach, J. A., Heinberg, L. J., Richter, D., Lawrence, J. W., Bryant, A. G., & Spence, R. J. (2002). Coping with body image changes following a disfiguring burn injury. *Health Psychology, 21*(2), 115-121.

Fauerbach, J. A., Heinberg, L. J., Lawrence, J. W., Munster, A. M., Palombo, D. A., Richter, D., . . . Muehlberger, T. (2000). Effect of early body image dissatisfaction on subsequent psychological and physical adjustment after disfiguring injury. *Psychomatic Medicine, 62,* 576-582.

Fearmonti, R., Bond, J., Erdmann, D., & Levinson, H. (2010). A review of scar scales and scar

measuring devices. *ePlasty.* Retrieved from http://www.eplasty.com/index.php?option=com_content&view=article&id=457&catid=171:volume-10-eplasty-2010&Itemid=121

Finucane, M. L. Slovic, P, & Mertz, C. K. (2000). Public perception of the risk of blood transfusion. *Transfusion, 40*(8), 1017-1022. doi: 10.1046/j.1537-2995.2000.40081017.x

Forbes-Duchart, L., Marshall, S., Strock, A., & Cooper, J. E. (2009). Burn therapists' opinion on the application and essential characteristics of a burn scar outcome measure. *Journal of Burn Care & Research*, *30*(5), 792-800. doi: 10.1097/BCR.0b013E318053D3BB

Fortier, J. L. & Castiglione, C. (2012). Skin grafting. *Techniques in Orthopaedics, 27*(4), 244-249.

Gabriel, V. (2011). Hypertrophic scar. *Physcial Medicine and Rehabilitaiton Clinics of North America, 22*, 301-310. doi:10.1016/j.pmr.2010.02.002

Guba, E. G. & Lincoln, Y. S. (1981). *Effective Evaluation.* San Fransico, CA: Jossey-Bass Inc.

Jootun, D. & McGhee, G. (2009). Reflexivity: Promoting rigour in qualitative research. *Nursing Standard, 23*(23), 42-46. Retrieved from http://nursingstandard.rcnpublishing.co.uk/archive/article-reflexivity-promoting-rigour-in-qualitative-research

Kalus, A., Aindow, J., & Caulfield, M.R. (1979). Application of ultrasound in assessing burn depth. *The Lancet*, *1*, 188-189. doi:10.1016/S0140-6736(79)90583-X

Katz, S. M., Frank, D. H., Leopold, G. R., & Wachtel, T. L. (1985). Objective measurement of hypertrophic burn scar: A preliminary study of tonometry and ultrasonography. [Comparative Study]. *Annals of Plastic Surgery, 14*(2), 121-127. Retrieved from http://sfxhosted.exlibrisgroup.com.ezproxy.lib.ucalgary.ca/calgary?sid=Entrez:PubMed&id=pmid:3888034

Kildal, M., Andersson, G., Fugl-Meyer, A.R., Lannerstam, K., & Gerdin, B. (2001). Development of a brief version of the burn specific health scale (BSHS-B). *Journal of Truama, 51*(4), 740-746. Retrieved from http://ovidsp.tx.ovid.com.ezproxy.lib.ucalgary.ca/sp3.8.1a/ovidweb.cgi?WebLinkFrameset=1&S=BALOFPLGCDDDKHEKNCOKOCDCOLCGAA00&returnUrl=ovidweb.cgi%3f%26Full%2bText%3dL%257cS.sh.18.19%257c0%257c000053732001100000020%26S%3dBALOFPLGCDDDKHEKNCOKOCDCOLCGAA00&directlink=http%3a%2f%2fgraphics.tx.ovid.com%2fovftpdfs%2ffFPDDNCDCOCEKCD00%2ffs033%2fovft%2flive%2fgv017%2f00005373%2f00005373200110000000020.pdf&filename=Development+of+a+Brief+Version+of+the+Burn+Specific+Health+Scale+%28BSHSB%29.&pdf_key=FPDDNCDCOCEKCD00&pdf_index=/fs033/ovft/live/gv017/00005373/00005373-200110000-00020

Koch, T. & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing, 28*(4), 882-890.

Kwon, B. K., Ghag, A., Reichl, L., Dvorak, M. F. Illes, J., & Tetzlaff, W. (2012). Options on the preclinical evaluation of novel therapies for spinal cord injury- a comparisson between researchers and spinal cord individuals. *Journal of Neurotrauma, 29*(14), 2367-2374. doi: 10.1089/neu.2012.2479

Ladak, A. & Tredget, E. E. (2009). Pathophysiology and management of the burn scar. *Clinics in Plastic Surgery, 36*, 661-674.

Lawrence, Fauerbach, Heinberg, & Doctor (2004). Visible vs hidden scars and their relation to body esteem. *Journal of Burn Care & Rehabilitation, 25*(1), 25-32.

Lawrence, J. W., Heinberg, L. J., Roca, R., Munster, A., Spence, R., & Fauerbach, J. A. (1998).

Development and validation of the satisfaction with appearance scale assessing body image among burn-injured patients. *Psychological Assessment, 10*(1), 64-70. doi: 1040-3590/98

Lau, J. C. M., Li-Tsang, C. W. P., & Zheng, Y. P. (2005). Application of tissue ultrasound palpation system (TUPS) in objective scar evaluation. [Research Support, Non-U.S. Gov't Validation Studies]. *Burns, 31*(4), 445-452. doi:10.1016/j.burns.2004.07.016

Lazarus, R. S. (1993). Coping theory and research: past, present, and future. *Psychosomatic Medicine, 55*, 234-247.

Loiselle & Profetto-McGrath (2011). *Polit & Beck Canadian essenstials of nurisng research* (3rd ed.). London, ON: Lippincott Williams & Wilkins.

Mann, E. M. & Carr, C. J. (2009). *Pain: creative approaches to effective management* (2nd ed.). London, UK: Palgrave Macmillian.

Martin, D., Umraw, N., Gomez, M., & Cartotto, R. (2003). Changes in subjective vs objective burn scar assesssment over time: does the patent agree with what we think? *Journal of Burn Care & Rehabilitation, 24*(4), 239-244. doi: 10.1097/01.BCR.0000075842.55039.03

Meerberg, G. A. (1993). Quality of life: a concept analysis. *Journal of Advanced Nursing, 18,* 32-38. doi:10.1046/j.1365-2648.1993.18010032.x/pdf

Moi, A. L. & Gjengedal, E. (2008). Life after burn injury: striving for regained freedom. *Qualitative Health Research*, *18*(12),1621–1630. doi:10.1177/1049732308326652

Moi, A. L., Vindenes, H. A., & Gjengedal, E. (2008). The experience of life after burn injury: a new bodily awareness. *Journal of Advanced Nursing*, *64*(3), 278–286.

doi: 10.1111/j.1365-2648.2008.04807.x

Morse, J. M. (ed.) (1994). *Critical Issues in Qualitative Research Methods.* Thousand Oaks, CA: SAGE Publications Inc.

Muller, M., Gahankari, & Herndon, D. N. (2007). Operative wound management. In *Total Burn Care* (3rd ed.) pp 177-195. Philadelphia, PA: Elsevier.

Munster, A. M., Horowitz, M. S. W., Tudahl, L. A. (1987). The abbreviated burn specific health scale. *The Journal of Trauma, 27*(4), 425-428.

Nedelec, B., Correa, J. A., Rachelska, G., Armour, A., & LaSalle, L. (2008). Quantitative measurement of hypertrophic scar: intrarater reliability, sensitivity, and specificity. *Journal of burn care & research*, *29*(3), 489-500. doi: 10.1097/BCR.0b013e3181710869

Omnell Persson, M., Persson, N. H., Ranstam, J., & Hermeren, G. (2003). Xenotransplantation public perceptions: rather cells than organs. *Xenotransplantation, 10,* 72-79. doi: 10.1034/j.1399-3089.2003.01132.x

Packer, M. J. & Addison, R. B. (Eds) (1989). *Entering the circle: Heurmeneutic investigation psychology.* Albany, NY: State University of New York Press.

Patterson, D. R., Hoflund, H. W., Espey, K., & Sharar, S. (2004). Pain management. *Burns, 30*(8), A10-A15. doi: 10.1016/j.burns.2004.08.004

Philip, L., Umraw, N., & Cartotto, R. (2012). Late outcomes after grafting of the severely burned face: a quality improvement initiative. *Journal of Burn Care & Research, 33*(1), 46-56. doi: 10.1097/BCR.0b013e318234d89f

Phoenix Society for Burn Survivors (2007). Survivors offering assistance in recovery. Retrieved from http://www.phoenix-society.org/programs/soar/

Rallan, D., & Harland, C. C. (2003). Ultrasound in dermatology--basic principles and applications. *Clinical & Experimental Dermatology, 28*(6), 632-638. doi: 10.1046/j.1365-2230.2003.01405.x

Ratner, Desiree. (1998). Skin grafting: from here to there. *Dermatologic Clinics, 16*(1), 75-90.

Richardson, P. & Mustard, L. (2009). The management of pain in the burns unit. *Burns, 35,* 921-936. doi: 10.1016/j.burns.2009.03.003

Rosenbach, C & Renneberg, B. (2008). Postive change after severe burn injuries. *Journal of Burn Care & Research, 29*(4), 638-648. doi: 10.1097/BCR.0b013e31817de275

Sainsbury, D. C. (2008). Body image and facial burns. *Advances in Wound Care, 22*, 39-44. Retrieved from http://adteaching.informatik.unifreiburg.de/zbmed/LWW/gv023/00129334/00129334-200901000-00012.pdf

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23,* 334-340.

Sandelowski, M. & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research, 13*, 905-923. doi: 10.1177/104973230253488

Sherwood, L. (2004). *Human Physiology: from cells to systems 5th ed.* Belmont, CA: Thompson Learning.

Smith, S. (2006). Encouraging the use of reflexivity in the writing up of qualitative research. *International Journal of Therapy and Rehabilitation, 13*(5), 209-215.

Smith-Harris, M. (Producer & Director) & Harris, B. (Producer) (2012). *Trial by fire: lives re-forged.* United States of America: Pyewackitt Productions.

Streubert, H. J. & Rinaldi Carpenter, D. (2011). *Qualtitative research in nursing: advancing the humanistic imperative.* Philadelphia, PA: Lippincott Williams & Wilkins.

Sullivan, T., Smith, J., Kermode, J., McIver, E., & Courtemanche, D. J. (1990). Rating the burn scar. *Journal of Burn Care & Rehabilitation, 11*(3), 256-260. Retrieved from http://sfxhosted.exlibrisgroup.com/calgary?sid=OVID:Ovid+MEDLINE%28R%29&id=pmid:2373734&id=doi:&issn=15345939&isbn=&volume=11&issue=3&spage=256&pages=25660&date=1990&title=Journal+of+Burn+Care+%26+Rehabilitation&atitle=Rating+the+burn+scar.&aulast=Sullivan&pid=%3Cauthor%3ESullivan+T%3BSmith+J%3BKermode+J%3BMcIver+E%3BCourtemanche+DJ%3C%2Fauthor%3E&%3CAN%3E2373734%3C%2FAN%3E

Summer, G. J., Puntillo, K. A., Miaskowski, C., Green, P. G. & Levine, J. D. (2007). Burn injury pain: the continuing challenge. *The Journal of Pain, 8*(7), 533-548. doi: 10.1016/j.jpain.2007.02.426.

Synder, R. J., Doyle, H., Delbridge, T. (2001). Applying split thickness skin grafts: a step-by-step guide and nursing implications. *Ostomy Wound Management, 47*(11), 20-26. Retrieved from http://www.o-wm.com/article/1080?page=0,0

Tengvall, O., Wickman, M., Wengstrom, Y. (2010). Memories of pain after burn injury--the patient's experience. *Journal of Burn Care & Research, 31*(2), 319-327. doi: 10.1097/BCR.0b013e3181d0f5dd

Thorne, S., Reimer-Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health, 20,* 169-177

Thorne, S. (2008). *Interpretive Design.* Walnut Creek, CA: Left Coast Press Inc.

Thorne, S., Oliffe, J., Kim-Sing, C., Hislop, T. G., Stajduhar, H., Harris, S. R., Armstrong, E. A.

& Oglov, V. (2010). Helpful communications during the diagnostic period: an description of patient preferences. *European Journal of Cancer Care, 19*, 746-754. doi: 10.1111/j.1365-2354.2009.01125.x

Thorne, S. Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1). Retrieved November 1, 2012 from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf

Thorne, S., Reimer Kirkham, S., & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*, 169-177.

Thombs, B. D., Notes, L. D., Lawrence, J. W., Magyar-Russell, G., Bresnick, M. G., & Fauerbach, J. A. (2008). From survival to socialization: a longitudinal study of body image in survivors of severe burn injury. *Journal of Psychometric Research, 64*, 205-212. doi: 10.1016/j.jpsychores.2007.09.003.

Timar-Banu, O., Beauregard, H., Tousignant, J., Lassonde, M., Harris, P., Viau, G., Vachon, L., Levy, E., Abribat, T. (2001). Development of noninvasive and quantitative methodologies for the assessment of chronic ulcers and scars in humans. *Wound Repair and Regeneration, 9*(2), 123-32. doi: 10.1046/j.1524-475x.2001.00123.x

van de Kar, A. L., Corion, L. U. M., Smeulders, M. J. C., Draaijers, L. J., van der Horst, C. M. A. M., & van Zuijlen, P. P. M. (2005). Reliable and feasible evaluation of linear scars by the Patient and Observer Scar Assessment Scale. *Plastic & Reconstructive Surgery, 116*(2), 514-522. doi: 10.1097/01.prs.0000172982.43599.d6

Van den Kerckhove, E., Staes, F., Flour, M., Stappaerts, K. & Boeckx, W. (2003) Reproducibility of repeated measurements on post-burn scars with Dermascan C. *Skin research and technology*, *9*(1), 81-84. doi: 10.1034/j.1600-0846.2003.00375.x

Wang, X.-Q., Mill, J., Kravchuk, O., & Kimble, R. M. Ultrasound assessed thickness of burn scars in association with laser Doppler imaging determined depth of burns in paediatric patients. [Research Support, Non-U.S. Gov't]. *Burns, 36*(8), 1254-1262. doi:10.1016/j.burns.2010.05.018

Wax, M. K., Pittman, A. L., & Ghanem, T. A. (2013). Split thickness skin grafts. Retrieved from http://emedicine.medscape.com/article/876290-overview

Wiechman, S. A. (2011). Psychosocial recovery, pain, and itch after burn injuries. *Physical Medicine and Rehabilitation Clinics of North America, 22*, 327-345.

Williams, N. R., Davey, M. & Klock-Powell, K. (2003). Rising from the ashes: stories of recovery, adaptation and resiliency in burn survivors. *Social Work in Health Care, 36*(4), 53-77. doi: 10.1300/J010v36n04_04

Xie, B., Xiao, S., Zhu, S., & Xia, Z. (2011). Evaluation of long term health-related quality of life in extensive burns: a 12-year experience in a burn center. *Burns,* Article in press. doi:10.1016/j.burns.2011.09.003

Yoder, L. H., Nayback, A. M., & Gaylord, K. (2010). The evolution and utility of the burn specific health scale: a systematic review. *Burns, 36,* 1143-1156. doi:10.1016/j.burns.2010.01.004

Yuxiang, L., Lingjun, Z., Lu, T., Mengjie, L., Xing, M., Fengping, S., Jing, C., Xianli, M., Jijun, Z. (2012). Burn patients' experience of pain management: a qualitative study. *Burns, 38,* 180-186. doi: 10.1016/j.burns.2011.09.006

Zachariah, J. R., Lakshmana Rao, A., Prabha, R., Gupta, A, Kingsly Paul, M., & Lamba, S. (2012). Post burn pruritus- a review of current treatment options. *Burns,* Article in press. doi: 10.1016/j.burns.2011.12.003

Appendices A: Interview Guide

Demographic data collected from chart: Sex, age, percent total body surface area (TBSA) burned, ethnic background.

Review confidentiality and consent on tape recorder.

Reminder that we have a burn unit psychologist.

Tell me about your burn injury. (will want to find out the date of injury, mechanism of injury, initial management)

Describe your experience as a burn patient.

Tell me about your surgical experiences.

Tell me what your expectations of receiving a split thickness skin graft were.

How did you feel about the STSG when the dressing was removed?

What did the HCPs (MDs, nurses, therapists) say?

How did the graft look to you?

What was it like recovering from surgery after receiving a skin graft.

What about the donor site?

How was your post-operative pain managed?

Tell me what you expected from your skin graft(s)

Tell me how you feel about the skin grafts(s)

1) appearance (colour, texture)
2) sensation
3) pain
4) itchiness
5) function

How did you feel about the graft(s) as it/they changed over time?

Is how other people feel about your skin graft important to you?

How do you think other people feel about your skin graft?

If you could change one thing about your skin graft what would it be and why? Is there anything else you would change and why?

What risk are you willing to take to change your skin graft? (for example another surgery, participate in further research/clinical trials).

During the last part of the interview I would like to ask you your opinion on stem cell therapies, is that ok with you?

What is your opinion/attitude toward receiving a skin substitute that would be (Clover et al., 2012):

a) derived from cells that are your own?
b) derived from cells from a family member?
c) derived from cells from a close friend?
d) derived from cells from a stranger?
e) derived from cells from the umbilical cord blood of a healthy infant?
f) derived from cells from a human embryo specifically created for providing cells for skin regeneration?

What is your opinion/attitude toward receiving a skin substitute that would be derived from cells from an animal (Clover et al., 2012), for example a pig?

What would be sufficient evidence to do experiments in humans for you to be comfortable with? For example, as long as the cells were effective in a small animal model (eg. rat or mouse), would that be enough evidence to try it in humans. A small animal model is not enough they should also be effective in a large animal model (e.g. pig, sheep, or rabbit) (Kwon et al., 2011). Please explain.

Appendices B: Selected Excerpts of Coded Transcript

Participant Jane

Interviewer: Do you recall before you got the surgeries, the explanations that took place? You know, we are going to take skin from an area and move it here . . . had you heard of a skin graft?	
Participant #12: I . . . oh, no, I hadn't heard of a skin graft – and I really didn't get – I think it was my daughters that got the explanation because I wasn't able to comprehend. They had me very heavily sedated. It was kind of – now, just let me think here for a minute. You know, I don't think that – I don't recall anyone actually coming in and saying this is what has happened to you or this is what we are going to do to you or anything like that. I think I just kind of – a little bit of explanation from my daughters, some explanation, little bits, from nurses and stuff and doctors. I do remember after my surgeries, 'cause they took donor skin from my bum and, oh my goodness, it was so sore. Actually, I recall, that the donor sites were more painful than the burn sites actually, in my recollection, especially my bum. My bottom was just – it was so sore and I remember asking, why is it so sore? And then they told me that that was where they had taken the donor skin from and it was, you know, very, very sensitive – like having a really bad sunburn or like an open wound or whatever and so then they did do a little bit of explaining then. But there was not really a time when, you know, they came in and said, okay, this is what happened, this is what – I don't really recall that.	Heavily sedated, therefore may not be able to recollect discussions that did in fact take place (informed consent) Donor site pain a recurrent theme, donor site pain remembered as being more painful than burns. Rely on family to fill in the pieces.
Interviewer: Do you remember when your dressings came down for the first time then and seeing your skin grafts or your burn scars for the first time and what that was like?	
Participant #12: That was very emotional. I did not understand the extent of my injuries. I really didn't and even, I think for me, I just	Very powerful emotions come through in the participants response: - Denial

kind of – of course, everybody handles it differently. But, for me, I didn't really – I tried to just push it away kind of – I didn't come to terms with it – well, I would say maybe even as short a time as six months ago where I finally could just say to myself – well, this is the way it is. And up until that time, it was like – why me? I just want my old life back. And just not really – feeling very uncomfortable and very – like, I remember for the longest time I had a knot in my stomach. It was just always there and I had a hard time sitting still and I had a hard time – relaxation was just not a term that I even thought about. I had to just keep on going. I think that was what it was. I just wanted to keep on going, just so that I could – just thinking I've got to get better and I've got to, you know, I want everything healed and I just want to get on with my life. I just want to get on with my life.	- Fear - Anxiety - Stress - Loss "I just want my old life back" Not wanting to be seen in public Desire to move forward, beyond the injury
Participant #12: He didn't know me any other way. So he didn't question. He doesn't look at me and say, what's that Nana? You know, so I can go around the house without – but for the longest time, I didn't even like having my head exposed to my family. I would wear little, you know, just some kind of a little scarf or something around my head, even in the house, 'cause I just didn't – I was very self-conscious about – especially my head.	Insecure to show appearance/new skin to family
Participant #12: Hair is a big part of a woman's whole look and its tough, but I just look at the things that I still do have. I look at the fact that I can still walk and I can still carry my grandson and care for my grandson and I didn't suffer any brain injury. I have to sometimes look at what I have instead of – or what – I have to sometimes look at, yeah, what I have instead of what I don't have, yeah.	"it could have been worse"… its unfortunate to have a large part of identity taken away… Look at what I have instead of what I don't have
Participant #12: …And so that's what I have to focus on and, you know, at the beginning, sometimes it was one hour at a time. Just get through this hour, just get through this dressing change, then we'll deal with what happens	

next. Now I'm finally to the point where I am starting to look a little bit more into the future and realizing that, yeah, there is going to be a life after recovery and my life will go on and so I'm getting to that point. Thank goodness.	
Interviewer: Good.	
Participant #12: Yeah.	
Interviewer: So in these last, you know, couple of years then, how have the grafts evolved? You've talked about the appearance and how you are becoming a little bit more comfortable with it. What about things like sensation, the sensation of the grafts? Does it feel the same as your regular skin? Do you notice any difference there?	
Participant #12: One thing I do find is that I sweat now. I was not a sweater. Before the accident, I didn't sweat. But now, especially on my forehead, if I get warm, and I do get warm fairly regularly, I sweat on my forehead and on my face and I can feel it. I had just gone through menopause not too long before the accident so I did experience hot spells, hot flashes. And they are a little bit similar to that. It could be some hormonal thing but I do believe that because my grafts aren't breathing properly and they don't have the sweat glands, my other parts of my body are sweating more	Due to lack of dermis in STSG
Interviewer: Yup.	
Participant #12: . . . to compensate for that. Sensation – this leg I don't have a whole, like I have smaller grafts on this leg, so this leg isn't bad. With this leg, and I'm wondering if maybe the graft was deeper – the burn was deeper – I'm not sure, but right up in this area, I still have – it's still a little bit inflamed. It's still a little bit red and a little bit dry. It's getting better but I do still wear my garments, say at night.	STSG: red, itchy
Interviewer: Okay.	
Participant #12: Yeah. I don't' go without my garments for any length of time, yet. I'm hoping by this summer I will be able to. But it's sensitive. It's very sensitive. If I just bump it a little bit, it certainly is, yeah. But I	STSG: very sensitive

was a person who bruised very easily before the accident anyway so, you know, I just had to bump myself and I'd get a bruise. So, I mean, I've always been pretty sensitive. And from here, and I've got a graft up my back too, and it's very stiff – very tight. When I bend like this, you can see the stretch - you can just see it. But it's getting a little bit better.	STSG: stiff/tight
Interviewer: Good.	
Participant #12: I work it. I do a stretch. I try to do a couple stretches at various times throughout the day.	Importance of stretching to maintain function
Interviewer: Good.	
Participant #12: It's liveable. It's not the body I had, but it's not a handicap per se. I want to start doing some yoga. I'm thinking that that might help, maybe.	"It not the body I had" – new skin. A new normal
Interviewer: Good. I wonder. I bet.	
Participant #12: Yeah. And I keep it, well, lots of lotion.	
Interviewer: Yeah.	
Participant #12: And oil.	
Interviewer: Were you getting quite a bit of itchiness too, if you don't use a lotion or . . .?	
Participant #12: Well, I've never given it a chance 'cause I always use lotion. I don't go without lotion. I can see it getting itchy if there wasn't lotion on. Even if I get out of the shower and, say, put my makeup on or something, if I wait a little bit before I put lotion on, I can see where it would get itchy – 'cause it gets a little bit itchy if I wait even 10 minutes, so I can see where that might happen. But I don't ever go without lotion.	Lifelong adjustment to make. Result of lack of dermis in STSG
Interviewer: Just like the sweat glands, you don't have the same oil glands either…	
Participant #12: That's right. That's right, exactly. So I keep it very well lubricated.	
Interviewer: Okay. What about pain? Even up until this point, do you have any pain?	
Participant #12: No, not really to speak of. Unless I bump it or my head is still very sensitive. I'm very, very careful with my head. But as far as, if I'm just sitting, like right now	Physiologically, sensation can elicit a pain response

sitting here, I really can't say that I'm in pain. I can feel them. You know, it still feels tight.	
Interviewer: Yeah, I've heard that.	
Participant #12: Yes, you definitely know that they are there, but I wouldn't actually call it painful.	Not pain, but the sensation is altered
Interviewer: …you are still struggling with some open wounds though, to your head that we have discussed?	
Participant #12: … I want to get to the point with my head graft where I can wear wigs and not have to worry about it breaking down. By the sounds of it, there is always going to be a little bit of issues and I just have to deal with that.	Fragility of STSG is affecting appearance for this participant
Interviewer: Hopefully they can be minimized.	
Participant #12: Exactly. That's what I want – to be minimized.	
Interviewer: So if there was one thing you could change about your skin grafts, what would that be?	
Participant #12: Well, that they are not so tight – that would be nice, and the breakdown.	STSG priority concern= breakdown (fragility/durability) Next the tightness (elasticity)
Interviewer: Yeah.	
Participant #12: The breakdown would be the number one thing.	
Interviewer: Yeah.	
Participant #12: And then, like I say, the tightness of the . . . there's lots of things, actually.	
Participant #12: …So, my body, I say 50% of my body is . . . even more, ever higher . . . I may be 60-65% of my body is . . .	Over 60% of body contains wounds with a 30% burn to account for donor sites
Interviewer: Wounds.	
Participant #12: It's altered. It will never be the same as it was.	A new normal
Interviewer: And is seems like you are returning to some of your other activities though.	
Participant #12: Well, yes, I'm sure trying to. I'm really working hard at getting back to, you know, it's always going to be **a new normal**, but I'm trying to, yes, resume a life for myself.	

Interviewer: Good. Okay, that's kind of it for the skin graft questions, unless there is anything else you would like to add?	
Participant #12: I don't think so. No, not that I can think of.	